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ABSTRACT

The document contains 18 presentations from Southwestern Region Deaf-Blind Center workshops held from 1970 to 1973 and covering the areas of assessment, vision, auditory training, communication, learning, family, and problems. Entries included the following titles and authors: "Methods for Assessing the Status and Growth of Preschool Deaf-Blind Children" (F. Elzey); "Audiologic Assessment of Deaf-Blind Babies" (A. McClatchie); "The Rubella Child: An Ophthalmologic View" (J. Donin); "What Do You See?" (E. Jackson); "Auditory Function and the Deaf-Blind Child" (B. Franklin); "Residual Hearing and Auditory Training" (B. Franklin); "Auditory Testing for the Multi-Handicapped" (M. Lowell); "A Parental Guide to the Auditory Training in the Deaf-Blind Child, Not So Much a Program--More an Attitude" (A. McClatchie); "Language: A Comprehensive Approach" (L. Anderson); "The Role of Vision in Communication with Deaf-Blind Children" (A. Galloway); "Total Communication and Conceptual Learning" (R. Howell); "Language--What Is It?" (S. Kirchner); "Basic Steps in Building Communication" (S. Meyer); "Play as a Learning Experience" (B. Gold); "Program Planning for the Multi-Handicapped Child" (C. Hatcher); "Psychosocial Problems of the Handicapped Child and His Family" (J. Call); and "Problems in the Raising of Deaf-Blind Children" (A. Nemon). (SW)

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SOUTHWESTERN REGION DEAF-BLIND CENTER

SELECTED WORKSHOP PAPERS
1970-1973

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SEPTEMBER, 1974

FOREWORD

The Southwestern Region Deaf-Blind Center, established to provide a comprehensive regional system of services for deaf-blind children who live in California, Nevada, Arizona, Hawaii, American Samoa, Guam, and the Trust Territories, conducts numerous workshops and conferences for parents, teachers, aides, and other persons interested in or working with deaf-blind children. Serving such a wide geographic area makes it impractical for all interested persons to come together at one time for workshops or even to attend workshops given in various areas of the region during the school year.

The publication of selected workshop presentations, such as this, is then an alternative means of disseminating information to all concerned with deaf-blind children. Recognizing that the printing of presentations does not allow the full exchange of ideas and thoughts that the workshop setting allows, comments and questions regarding the material contained herein are solicited.

The comments and ideas expressed herein are not necessarily those of the Department of Health Education and Welfare, the Bureau of Education for the Handicapped, the California Department of Education, nor of the Southwestern Region Deaf-Blind Center, but those of the individual authors only.

If in some small way the material presented here aids parents or professionals working with deaf-blind children or interests someone in the deaf-blind field, it will have achieved its purpose.

Acknowledgement of all those who have cooperated so full heartedly in preparing presentations, organizing, and attending workshops of the Center, are so numerous as to require another volume in itself. Suffice to say "thank you" to all those involved in providing of services to the deaf-blind children in the Southwestern Region.

William A. Blea
Project Director

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Methods for Assessing the Status and Growth
of Preschool Deaf-Blind Children

Freeman F. Elzey

During the course of the past two years San Francisco State College has been engaged in an experimental education program in classroom instruction for preschool deaf-blind children. The project is funded by the U.S. Office of Education and its director is Dr. Eileen Jackson. All but one of the children enrolled in the program are the result of maternal rubella during the early months of pregnancy.

During the course of the project, several evaluational devices were developed in order to provide status assessments of the children at several time points throughout the school period as well as to detect growth of the children during their school experience. Because of the widespread interest in these evaluational instruments it is felt that their usefulness could be enhanced if they were shared with other preschool deaf-blind programs. Accordingly, this paper will present four instruments utilized in this project with the hope that they will be of value as models for use in other programs.

All of the instruments here described were developed in connection with the Deaf-Blind Preschool Project, USOE #OEG-O-9-142147-3740(032), at San Francisco State College, Department of Special Education, and can be reproduced for use in other evaluation efforts.

The first two instruments are relatively simple devices for recording the observation of a child during one learning experience. Attachment A presents the "Report of Learning Experience" form on which is recorded one observation of a finger painting activity. The observation record is divided into four main sections: 1) Materials or Equipment. In this section are listed all of the materials used by the child and adult. 2) Setting. The physical arrangement and other pertinent details of the environmental aspects of the location are noted here. 3) Description. In this section is listed the sequential description of the activity. Particular care is given to

objective description of the interaction of the child with the adult(s) and/or material. Where possible, verbatim accounts of the verbal communications are recorded. 4) Child Learning Experiences. An attempt is made to note the types of learning experiences that this particular activity provides for the child. In addition, the observer makes a judgement on the degree of involvement, self-direction, and activity level of the child during the activity. Space is provided for additional comments and interpretations.

A second instrument presents a method of recording observation of a child's performance at various time points on one type of activity. The form presented in Attachment B is for the activity of dressing and undressing. This format can be adapted for use with any activity. A coding system is provided which indicates the degree to which the child can perform various activities and also makes provision for the teacher to set "temporary goals" for the child. This form is particularly helpful where there are a number of adults involved with a group of children, in that a glance at this form for a particular child can provide a quick familiarization with the child's level of functioning in particular activities. If ratings are dated, they can provide a growth record of the child and can be revised when necessary, thus giving the child's current status in all of the activities listed.

The next two instruments to be described are the more formal assessment devices developed during this project and are presented here in detail in order that they may serve as models to other programs in assessing deaf-blind children.

Attachment C presents the Personal and Social Development Scale for Young Children with Multiple Sensory Impairment. It is designed for use in rating the personal and social development of young children with multiple sensory impairment from the chronological age of one year until approximately seven or eight years, depending upon the severity of the impairment.

The scale contains 54 items which are representative samples of the critical behaviors in the child's functioning. The items cover a wide range of behaviors, such as response to routine, independence in mobility, intellectual awareness, and social communication. Although the items were devised so as to be observable within the context of a school program, the importance of the behaviors transcends this specific environment.

Each item contains a series of descriptive statements which represent varying degrees of competence relative to the behavior measured by that item. The items require observations of actual performance rather than inferences about presumed abilities or capacities. The performance to be rated is stated in behavioral terms, thereby minimizing subjectivity in the evaluational process and increasing the reliability of judgement.

No special text situations are required. It is appropriate for use by teachers, parents, and others. To use this scale effectively, the rater need only be familiar with the content areas covered in the scale, including the ordering of levels within each item. In determining

the rating for a child on a particular item, the rater should take into account the variety of contexts within which the behavior manifests itself. The nature of the items requires the rater to have had considerable opportunity to observe the child on a variety of situations.

The 54 items are divided into five areas of development: Self Help, Manipulation, Ambulation, Social Communication, and Cognitive Behavior. Component scores are obtained for each of these five areas.

In establishing scores for each of the subscales and for the total scale it should be noted that the items vary in the number of levels contained in them and that the subscales are comprised of different numbers of items. Therefore, in establishing scores for the subscales and the total scale it was necessary to develop a scoring system which would:

- 1) adjust the values of items having differing numbers of levels in order that all items carry equal weight in the subscale score.
- 2) adjust for the differing number of items in the subscales in order to give equal "weight" to each subscale when determining the total scale score.

To give equal weight to items in a subscale regardless of the number of levels contained in the items, the value of each item's levels was converted to a scale of 100 points. For example, in a four level item, level 1 = 0 points, level 2 = 33 points, level 3 = 67 points, and level 4 = 100 points. The corresponding "converted" scores assigned to various levels for different size items are given below.

VALUES OF ITEM RESPONSES

Number of choices for item.	Item response given								
	1	2	3	4	5	6	7	8	9
3	00	50	100						
4	00	33	67	100					
5	00	25	50	75	100				
6	00	20	40	60	80	100			
7	00	17	33	50	66	84	100		
8	00	14	29	43	58	71	86	100	
9	00	13	25	38	50	63	75	88	100

A subscale score is obtained by summing the "converted" scores of the items in that subscale and dividing by the number of items in the subscale. Thus, each subscale's "converted" score ranges from 0 to 100. The converted score for the total scale is determined by summing the subscale "converted" scores and dividing by 5, the number of subscales. Thus, the "converted" score for the total scale also ranges from 0 to 100, with equal weight being given to each of the subscales. The child's score on each subscale may be interpreted as either a percentage of total possible score or as the average item level reached when each item is worth 100 points. The total scale score represents an average of the subscale scores. The subscale scores should not be interpreted as a profile since the subscales are not equal in difficulty.

The child is to be rated on each item in terms of his habitual or typical performance. Thus, the ratings are to be based on cumulative observations of the child in his normal environment. Each item should be independently rated, regardless of the rating made on any other item.

The descriptive statements within each item of the scale are ordered by level of competence and are numbered consecutively from Level 1, representing the lowest behavioral level. The levels are cumulative, in that a child who, for example, is rated 4 on an item is presumed to be able to perform at all preceding levels. Thus only one level is to be selected for an item. When the rater has determined the appropriate level, he should enter that level number on the scoring sheet in the box next to the appropriate item number. For the ratings to be of maximal value, it is necessary that the child be RATED ON EVERY ITEM in the scale.

The fourth instrument to be presented in this report is titled the Observation Rating Instrument. It is a device which permits the systematic recording of the behavior of preschool children. This particular instrument was developed as a means for obtaining objective descriptions of individual children and their interaction with their school environment.

This multidimensional time sample instrument permits an observer to immediately record descriptive information regarding the child on a number of variables.

There are a number of categories within each variable among which the observer is to choose one as the most representative of the child's behavior during the rating period. The variables and their categories are listed below:

Type of Experience the Child is Having

Categories: None, Sensory, Manipulative, Large Muscle,
Social, Cognitive, Other

Child Involvement Level

Categories: None, Low, Medium, High

Other Direction

Categories: None, Helps, Instructs, Prohibits

Person Involved

Categories: None, Teacher, Assistant, Teacher, Parent, Other Adult, Other Child

Activity Level

Categories: None, Low, Moderate, High

Mobility

Categories: Prone, Sitting, Crawling, Standing, Walking Supported, Walking Unsupported, Running-Climbing

Self Direction

Categories: Low, Medium, High

Cognitive Behavior

Categories: None, Repetitive, Aimless-random, Exploratory-nondirective, Purposive-goal directed, Experimental, Problem-solving

Expressive Communication

Categories: None, Physical, Voice projection, Gestures, Speech

Effect

Categories: Anger-protest, Unhappiness, Mild Happiness, Happiness, None or Inappropriate

The observational instrument has two rating sheets: one for use in situations in which the child is provided with "Directed Learning Experiences" and one for "Unstructured Learning Experiences." Thus, the first decision an observer must make is whether the child's experience is directed or unstructured.

Inspection of the attached observation rating forms indicates that the form for "Directed Learning Experiences" differs slightly from that for "Unstructured Learning Experiences" in that it includes an additional variable which permits ratings on "Type of Experience That Has Been Planned For the Child." This permits differential ratings to be made on this variable and on "Type of Experience Child is Having." This distinction is necessary for rating situations where the child is having a different type of experience than that planned by the adult. For example, a teacher may be attempting to provide the child with a cognitive experience but is unsuccessful in involving the child in it. Rather, he may be having a sensory experience with the materials provided.

In addition, the observation rating form for unstructured Learning Experiences does not provide a category titled "Instructs" on the "Other Direction" variable.

A behavioral rating unit is one minute. During this period the rater observes the child for the first thirty seconds -- he used the second thirty seconds to record his ratings on the appropriate observation record form. Every variable is rated during each minute. Fifteen continuous minutes of observation and rating have been found to be an appropriate time period for sampling behavior, although the rating instrument permits any number of observation units to be recorded.

To facilitate the rating process, the variables are paired on a grid, one variable being on the horizontal axis and one on the vertical axis. By placing one tally mark in the grid the observer provides ratings on two variables. Thus, six tallies -- one in each of six grids -- provides a rating on twelve variables. After fifteen continuous minutes of observation each grid will contain fifteen tally marks, each mark representing ratings on two variables. Column totals and row totals for each grid yield the pattern of ratings over the fifteen minute period. These totals may be combined with other time sample observations for one child thus presenting an overall status rating over several time periods.

Because of the large number of judgments to be made and recorded by the observer in the short span of one minute, it is necessary that the observer be thoroughly versed in the definitions and criteria for rating prior to using this instrument.

Attachment D presents the definitions of categories within each of the variables for use as criteria in determining ratings. This attachment also presents the forms used for recording the observational data.

Attachment A

REPORT OF LEARNING EXPERIENCE

Child _____ Observer _____ Date _____
 Adult(s) _____ Length of Observation _____
 Type of Activity Finger painting

Materials or Equipment:

Finger paint in tubes. Large sheets of paper.

Setting:

Adult sits next to child at table. Large sheet of paper is taped to table. Child is wearing smock.

Description:

Adult squeezes paint out of tube. Puts tube in child's hand and squeezes his hand so paint comes out. Adult presses child's left hand into paint on paper and smears it in a circular motion. Adult talks quietly to child. "Make a round circle, big circle. Go round, round, round, _____, look what you are doing. That's a nice boy." Child does not make motion when adult stops guiding his hand. Adult shows child his hand with paint on it. Child frowns and tries to pull away. Looks out of window. Adult takes child by the hand and walks him to the sink. "Let's wash our hands." Adult assists in hand washing. Puts child's hand on water faucet and tries to get him to assist in turning water on and off. Says "On, off, on, off." Hands towel to child, "Dry your hands. That's a good boy." Child makes wiping motions. Adult takes off child's smock. Child walks away, toward the window.

Child Learning Experiences:

Sensory awareness. Following adult's verbal directions. Following adult's physical directions. Association of labels with objects, "circle, water, hands, etc." Experience in self help activity of hand washing and drying.

	<u>Low</u>				<u>High</u>
Child Involvement	1	2	3	4	5
Child Self Direction	1	2	3	4	5
Child Activity Level	1	2	3	4	5

Comments:

Adult did not force activity on child. Let him proceed at own pace. Could have spoken more to child--more repetition of terms. Child showed little interest. Maybe should have used more than one color. More experimentation needed at sink by child in order to get him involved in washing and drying.

Attachment B

Child _____

Date began record _____

Date ended record _____

UNDRESSING

	Jacket	Shoes	Socks	Pants	Under-pants	Shirt Top open	Shirt Front open
Passive, unaware							
Resistive, uncooperative							
1. Assistive, moves body limbs							
2. Awareness, cooperates, hand movements							
3. Follows through single movement							
4. Repeats initiated movement							
5. Follows through on series, adult directed							
6. Follows through on series, initial direction							
7. Initiates and follows through independently							

DRESSING

Passive, unaware							
Resistive, uncooperative							
1. Assistive, moves body limbs							
2. Awareness, cooperates, hand movements							
3. Follows through single movement							
4. Repeats initiated movement							
5. Follows through on series, adult directed							
6. Follows through on series, initial direction							
7. Initiates and follows through independently							

Code: - = not applicable X = usually does
 N = does not do O = temporary goal
 S = sometimes does

Attachment C

PERSONAL AND SOCIAL DEVELOPMENT SCALE
FOR YOUNG CHILDREN WITH MULTIPLE SENSORY IMPAIRMENT

SELF HELP1. DRESSING

1. Does not assist in dressing
2. Extends arms and legs when being dressed
3. Helps to pull on clothes
4. Puts on coat or simple garment, assisted
5. Puts on coat or simple garment, unassisted
6. Dresses self except for fastening
7. Dresses self including simple fastening

2. UNDRESSING

1. Does not assist in undressing
2. Extends arms and legs when being undressed
3. Helps to take off clothes
4. Takes off coat or simple garment, assisted
5. Takes off coat or simple garment, unassisted
6. Undresses self except for fastening
7. Undresses self including simple fastening

3. PUTTING ON SHOES

1. Does not put on shoes
2. Puts on shoes, assisted
3. Puts on shoes, unassisted
4. Puts on shoes, attempts to fasten or pull laces tight
5. Puts on shoes, makes first part of bow
6. Puts on shoes and ties bow knot

4. WASHING HANDS

1. Does not attempt to wash hands
2. Makes lathering motions if aided by adult
3. Turns on water and lathers hands unaided
4. Lathers hands and rinses unaided
5. Lathers, rinses and dries hands unaided

5. TOILET: ACCEPTING PROCEDURE

1. No opportunity - no attempt to train'
2. Will not sit on toilet or potty chair
3. Will sit on toilet or potty chair for a few minutes
4. Accepts being regularly placed on toilet once or more each day
5. Will wait to be taken to toilet

6. TOILET: BOWEL CONTROL

1. No opportunity - no attempt to train
2. Occasionally has bowel movement while on toilet or potty chair
3. Frequently has bowel movements on toilet when placed there on his time schedule
4. Usually has bowel movements on toilet when placed there on his time schedule
5. Has occasional toileting accidents
6. Rarely has an accident

7. TOILET: BLADDER CONTROL

1. No opportunity - no attempt
2. Occasionally urinates while sitting on toilet or potty chair
3. Frequently urinates in toilet when placed there on regular time schedule
4. Usually urinates in toilet when placed there on regular time schedule
5. Has occasional toileting accidents
6. Rarely has an accident

8. FEEDING: TABLE FOODS

1. Does not handle table foods
2. Puts cracker to mouth and sucks
3. Holds, munches on cracker or similar food
4. Will hand feed a variety of finger foods such as cookies, potato chips, popsicles

9. FEEDING: FOOD TEXTURES

1. Accepts only baby food
2. Accepts junior foods
3. Accepts mashed table foods: oatmeal
4. Accepts and somewhat chews lumpy foods: cottage cheese
5. Accepts and chews lumpy foods
6. Accepts and chews bite sized pieces of solid food

10. FEEDING: USE OF UTENSILS FOR EATING

1. Does not use utensils
2. Holds a spoon
3. Runs spoon across plate
4. uses spoon: spills, rotates, feeds self part of meal
5. Uses spoon with some spilling, no rotating
6. Uses spoon well
7. Uses fork to pierce pieces of food

8. Uses all table utensils except for cutting implements

11. FEEDING: DRINKING FROM CUP

1. Does not drink from cup
2. Drinks from cup held by adult
3. Helps to hold cup
4. Can hold cup for drinking; does not set down well
5. Picks up and sets down cup well, without much spilling

MANIPULATION12. RELEASING OBJECTS

1. Does not release objects; lets fall
2. Crude, deliberate release
3. Releases deliberately
4. Deliberate casting, throwing

13. INSPECTION OF ONE OBJECT

1. Does not manipulate objects
2. Manipulates objects with one hand
3. Transfers object from one hand to another
4. Inspects grasped object by feeling and rotating
5. Explores object with pointed finger

14. INSPECTION OF MORE THAN ONE OBJECT

1. Does not handle more than one object at a time
2. Holds one object in each hand
3. Can hold more than two objects at a time

15. EFFICIENCY OF AIM

1. Does not hold objects
2. Will hold object placed in hand
3. Raises and extends arms to pretend object
4. Can grasp object - faulty aim
5. Efficient aim when reaching for object

16. GRASP TYPE

1. Does not grasp
2. Palmar grasp
3. Radial palmer grasp (grasped against palm at base of thumb)
4. Radial digital grasp (grasped against base of thumb with index finger used)
5. "Adult grasp"

17. OBJECT USE: DOOR

1. Does not manipulate door
2. Pushes and pulls door
3. Grasps doorknob
4. Turns doorknob
5. Turns doorknob, opens door

18. OBJECT USE: CONTAINERS, OPENING AND CLOSING

1. Does not make use of containers
2. Opens very simple containers
3. Opens and closes very simple containers
4. Opens and closes a variety of containers

19. OBJECT USE: BALL

1. Will not use
2. Holds briefly
3. Rolls
4. Throws toward target

5. Catches bounced ball
6. Bounces and catches ball

20. OBJECT USE: EDUCATIONAL TOY PARTS

1. Does not use
2. Handles parts
3. Takes pieces out or apart
4. Makes attempt to assemble
5. Places one part correctly

AMBULATION21. SITTING

1. Does not sit
2. Sits supported in chair or lap
3. Sits supported on flat surface
4. Sits unsupported on flat surface
5. Achieves sitting position unassisted on flat surface
6. Sits freely

22. CHAIR SITTING

1. Does not sit in chair without support
2. Sits in chair without support
3. Can sit down and get up from chair with assistance
4. Climbs onto and sits in chair unassisted

23. CRAWLING

1. Does not move whole body in space
2. Rolls over
3. Moves self by rolling or by pushing or pulling body on floor
4. Achieves crawling position assisted
5. Achieves crawling position unassisted
6. Holds head up in crawling position

7. Crawls with assistance
8. Crawls unassisted for a few feet
9. Crawls freely in space

24. ADAPTIVE CRAWLING

1. Does not crawl
2. Crawls under and through large objects
3. Crawls over or around obstacles
4. Encircles, encompasses, large objects by using a combination of crawling and climbing

25. STANDING

1. Cannot stand
2. Puts weight on feet when body is held in standing position
3. Stands with maximal support from adult
4. Stands by grasping support with both hands
5. Stands by grasping support with one hand
6. Stands unsupported

26. RISING TO STANDING POSITION

1. Cannot rise to standing position
2. Rises to standing position with full adult assistance
3. Rises to standing position with adult assistance using one hand
4. Rises to standing position using large objects or railing for help
5. Rises to standing position without assistance

27. WALKING

1. Does not move in space on feet
2. Walks with a great deal of support by adult

3. Walks with minimal adult assistance
4. Walks while holding to large objects for support
5. Walks unassisted for a few feet
6. Walks unassisted

28. CLIMBING UPSTAIRS

1. Cannot climb upstairs
2. Climbs upstairs on hands and knees
3. Climbs upstairs if assisted by adult
4. Climbs upstairs using railing for support
5. Climbs upstairs without assistance

29. CLIMBING DOWNSTAIRS

1. Cannot climb downstairs
2. Climbs downstairs on hands and knees
3. Climbs downstairs is assisted by adult
4. Climbs downstairs using railing for support
5. Climbs downstairs without assistance

30. CLIMBING

1. Does not climb
2. Climbs only with assistance
3. Crawls up and down obstacles
4. Climbs onto and off of objects as high as adult size chair
5. Uses hands and feet in climbing
6. Climbs ladder or jungle gym unassisted

SOCIAL COMMUNICATION31. DIFFERENTIAL AWARENESS

1. Does not differentiate between people and objects
2. Differentiates people from objects but does not differentiate among people
3. Differentiates between mother or mother substitute and other adults
4. Differentiates between familiar and unfamiliar adults
5. Responds differently to different adults

32. RELATIONSHIP WITH CHILDREN

1. No awareness
2. Aware and avoids, moves away from other children
3. Aware and accepts presence of other children
4. Aware of activity of other child, as in parallel play
5. Plays with one other child, cooperative play
6. Plays with a group of children

33. INDICATING WANTS

1. No indication
2. Nonspecific whining, fussing
3. Whines, fusses, specifying wants
4. Pushes, pulls, reaches, to make wants known
5. Uses gestures to make wants known
6. Uses language to make wants known

34. RESPONSE TO ADULTS

1. Does not discriminate between positive and negative responses of adults

2. Discriminates between positive and negative responses of mother or mother substitute
3. Discriminates between positive and negative responses of other adults
4. Varies his behavior according to emotional reactions of other adults

35. INDICATING DISLIKES

1. No indication
2. Whines, fusses, pushes, shoves away, hits, bites, etc.
3. Uses gestures, shakes head
4. Uses language

36. EXPRESSIVE

1. Seldom vocalizes
2. Vocalizes with baby noises
3. Makes a variety of vocalizations
4. Attempts to mimic basic speech sounds
5. Repeats one-word sentences
6. Uses one-word sentences appropriately
7. Uses more than one-word sentences

37. RECEPTIVE

1. No receptive behavior
2. Fixates persons
3. Attends to voices for a brief period
4. Is aware of being addressed
5. Understands "no"
6. Usually understands and responds to simple commands

COGNITIVE38. TACTILE DISCRIMINATION

1. Does not touch objects
2. Touches objects
3. Handles a variety of objects
4. Compares shapes and other qualities by touch plus another sense
5. Compares shapes by touch alone

39. CONCEPT OF OBJECT USE

1. Will not accept, no interest
2. Holds briefly
3. Uses object for action (bangs shakes, mouthes)
4. Examines objects
5. Experiments, finds out what it will do
6. Uses objects for imagery, simple "pretends" (use of doll, hugs, spansks, etc.)
7. Representational play, uses objects to represent real things or situations (playing house)

40. IMITATION: GROSS MOTOR MOVEMENT (JUMPING, PATTY-CAKE)

1. Does not imitate
2. Imitates with assistance
3. Occasionally imitates without assistance
4. Frequently imitates without assistance

41. IMITATION: FINGER MOVEMENTS (TOUCHING NOSE, PICKING UP PEG)

1. Does not imitate
2. Imitates with assistance
3. Occasionally imitates without assistance
4. Frequently imitates without assistance

42. IMITATION: AUDITORY, VIBRATORY, VOCAL

1. Does not imitate
2. Imitates with assistance
3. Occasionally imitates without assistance
4. Frequently imitates without assistance

43. CURIOSITY: OBJECTS

1. Shows no curiosity
2. Handles objects when given or when comes in contact with
3. Some interest in objects, needs outside stimulation
4. Is curious about objects
5. Highly curious and investigative

44. CURIOSITY: EXPLORING ENVIRONMENT

1. Shows no curiosity
2. Little interest in exploring environment
3. Some interest in exploring, needs outside stimulation
4. Is curious about environment
5. Highly curious and investigative

45. USE OF IMPLEMENTS

1. Does not use implements (tools, utensils, etc.)
2. Uses implements only after trained in use by adult
3. Uses implements spontaneously in solving simple problems

46. AVOIDING OBSTACLES IN PATH

1. Does not avoid obstacles
2. Shows some awareness of obstacles but often cannot solve problem
3. Overcomes simple obstacles in the course of moving around
4. Shows ingenuity in getting around or avoiding obstacles in path

47. ATTENTION SPAN: OBJECTS (NOT PERSEVERATION)

1. Does not play with objects
2. Plays with one object very briefly
3. Can play with one object for up to one minute
4. Can play with one object for up to three minutes
5. Can play with one object for more than three minutes

48. ATTENTION SPAN: ADULT INVOLVED ACTIVITY

1. Does not attend to activity started by adult
2. Attends activity very briefly
3. Attends activity for up to one minute
4. Attends activity for up to three minutes
5. Attends activity for more than three minutes

49. PARTICIPATION IN GROUP ACTIVITY

1. Shows no awareness of group activity
2. Shows awareness of group activity by either negative or positive response to activity
3. Shows interest in participating in group activities

4. Anticipates group activity

50. OBEYING RULES

1. Unaware that rules exist
2. Aware of given rules but nonconforming
3. Tries to conform, needs support
4. Conforming to usual rules
5. Acceptance and flexibility in conforming

51. DIFFERENTIATING AMONG OBJECTS

1. Does not differentiate among objects in environment
2. Shows some choice of objects (like-dislike)
3. Recognizes some objects as played with in a special way
4. Differentiates among known objects in environment by use or function

52. PROBLEM SOLVING

1. Unaware of problems
2. Makes no attempt to solve problems
3. Random trial and error
4. Trial and error based on previous experiences
5. Assesses situation before moving and acting

53. REPRESENTATIONAL PLAY

1. Does not show any representational play
2. Shows recognition of simple representative objects
3. Demonstrates awareness of simple relationships between representational toys (sits in doll chair)
4. Acts out situations with pantomime and representative objects (dolls, cars, toy furniture), situations acted out are those which he himself has experienced.
5. Acts out on a level involving situations not personally, motorically experienced.
Uses imagination

54. ATTENDS BEHAVIOR OF OTHER:
PRE-IMITATIVE

1. Does not attend behavior of others
2. Occasionally ceases movement or turns toward behavior
3. Frequently ceases movement or turns toward behavior
4. Occasionally responds to behavior of others with pre-imitative behavior of his own
5. Frequently responds to behavior of others with imitative behavior of his own

Attachment D

CRITERIA FOR RATINGS

1. TYPE OF LEARNING ACTIVITY

In making ratings, the first decision to be made is whether the child was engaged in a directed learning experience or in an unstructured experience. Based upon this decision, the observer chooses the appropriate observation rating form for entering his ratings.

a. Directed Learning Experience: Any experience where there is evidence that an adult has either pre-planned an experience for the child and is attempting to carry out the planned activity, or has capitalized upon the child's chosen activity in order to further his scope of experiences or to provide him with additional material or techniques which broadens his awareness and knowledge. To qualify as a "directed learning experience" it is necessary that it be an outgrowth of a conscious effort on the adult's part to provide a meaningful learning experience for the child. This does not include helping the child to accomplish his goals or fulfill his desires where there is no evidence that the adult is using the situation to further the child's knowledge. Putting on a child's coat for him, putting objects within child's reach, or removing him from hazardous situations does not qualify as a directed learning experience. It is necessary that, in the judgment of the observer, there be a clear attempt by the adult to do more than merely facilitate the child's self occupation or insuring his safety.

b. Unstructured Learning Experience: Unstructured experiences are defined as those in which there is no apparent adult direction, either pre-planned or on-the-spot which is designed to enhance the growth of the child. All experiences initiated and sustained solely by the child are considered unstructured. Adults performing assistance or supervisorial functions, participating without attempting to teach the child, or to provide him with calculated experiences, are considered as unstructured experiences.

Ratings are made on the basis of the most prominent and sustained type of experience during a rating period. Where many types of experiences are occurring during a period, a judgment must be made as to which is predominant.

2. TYPE OF EXPERIENCE

For "Directed Learning Experiences" the rater must first judge the type of experience that has been planned for the child. That is, what is the type of activity that the adult sets out for the child to experience. This is to be distinguished from the type of experience the child is having, if the two types differ. If the child is, in fact, experiencing the planned activity, the "same" box under "Type of Experience Child is Having" is checked. If he is not having the planned experience, but is experiencing another type of activity, then that type is checked in "Type of Experience Child is Having." Thus, only where the child is experiencing an activity other than that planned for him, does the rater enter a rating in "Type of Experience Child is Having."

a. Sensory: Includes all activities in which sensory intake is the focus of the activity. Such experiences include auditory training, feeding (tasting different foods), touching, feeling, smelling.

b. Manipulative: Activities involving small objects in which the child is engaged in pushing, banging, putting-in, taking-out, picking-up, etc. Most table activities where the main focus is in small muscle movement as in handling small objects.

c. Large Muscle: Activities in which child is using whole body, as in bouncing ball, running, climbing, walking, crawling, stacking large blocks, pulling wagon, pushing large cart, etc.

d. Social: Any contact with another person in which the focus is primarily on interpersonal experience. Interaction with others, such as peek-a-boo. Dramatic play involving other people. Seeking comfort as in hugging. Trying to get another's attention by pulling, pushing, crying, objecting to what other is trying to do with him. Temper tantrums directed at a person. The interpersonal aspect must be predominant to qualify a rating for this category.

e. Cognitive: Activities in which the primary focus is on the intellectual process involved. Exploratory, purposive, experimental or problem solving behavior, where the thinking process is highly involved in the activity (as opposed to merely feeling, or rolling cars). Finding new ways to accomplish goals. Trying to figure out how something works.

f. Other: This category is used only in cases where the activity does not clearly fall into one of the above categories. When used, a note should be made on the rating form to indicate the nature of such activity.

3. CHILD INVOLVEMENT

Records the child's interest, degree of absorption, in the situation to which he is exposed during the observation period.

For Unstructured Learning Activities

In this situation the variable has four levels which indicate the degree of interest shown in an experience in which he is not directed by others.

- a. None: Child is not having any experience. The child does not appear to be engaged in any activity, even that of a seemingly meaningless nature.
- b. Low: Child is minimally occupied and/or is sporadic in attending to the activity. Exhibits little interest in, participation in, or awareness of the experience. Child may appear to be disinterested in the activity but is merely going through the motions.
- c. Medium: Child engages in an activity with some interest, occupies himself, shows moderate participation in experience.
- d. High: Child is actively engaged in an activity for which he shows sustained and intense interest, participation and awareness.

For Directed Learning Experiences

The involvement variable is recorded twice for the directed learning experience -- once to reflect involvement in the planned experience and once to indicate involvement in other, unplanned experience. The observer must decide whether the child is primarily engaged in having the planned experience or is having a different experience: the choice made for the first grid (planned) will limit those available for the second grid.

The criteria for the low, medium, and high categories are the same as those given previously for Unstructured Activity.

If the child is marked at the low, medium, or high level of involvement in the planned experience, he is placed at the SAME level in the second grid (experience child is having).

If the child is placed in the NONE category for the planned experience he is considered to have no involvement in this activity. He is then rated as to his actual experience by indicating the degree of involvement (none, low, medium, high) in the grid headed "type of experience child is having." A NONE rating in this box indicates, as it did in the unstructured situation, that the child is not engaging in any activity.

4. OTHER DIRECTION

a. None: The child is pursuing an activity on his own. There is no involvement with another person for the majority of the time period. Another person may be in the immediate vicinity of the child, but not interacting with him. Watching the child to see how he is doing should be rated as "none" if there is no direct involvement.

b. Helps: Other adult or child facilitates the child in his own activity by assisting him, picking up dropped toys, etc. The interaction must be basically non-instructive, such as putting on clothes, washing hands, opening jars, holding child for comfort. If there is an element of teaching involved in the behavior of the other person, it should be rated "Instructs."

c. Instructs: Other person demonstrates, directs child in practice, requires repetition, guides in order for learning to take place, providing word sounds to identify objects, provides auditory and speech training, shows child how to hold spoon and eat, etc. To qualify as instructive, a behavior must be such that the person is trying to impart knowledge or develop skill in the child.

d. Prohibits: Other adult restrains child, diverts him from undesirable activity. Removes child from situations, prevents him from pursuing his desired behavior. Holds child securely in order to try to get him to do something which he does not want to do.

5. PERSON INVOLVED

Where a person is involved with a child in an activity, the type of person is indicated in this section. To be rated as "involved" a person must have been working directly with the child for the majority of the time period. If more than two persons are involved with a child at the same time, a judgment must be made as to which was more highly involved. Only one rating is permitted for a given time period. The categories available for rating are: None, Teacher, Assistant Teacher, Parent, Other Adult, Other Child. The category "parent" refers to the

child's own parent. If a parent in the school is engaged in an activity with a child other than her own, she is rated as "Other Adult."

6. ACTIVITY LEVEL

This variable indicates the degree and intensity of the child's physical activity during the rating period.

- a. None: Child is motionless, lethargic. No apparent activity.
- b. Low: Child is stationary; either prone, sitting or standing. amount of movement is minimal. Child may be highly involved but amount of actual physical exertion is low.
- c. Moderate: Child moves at a deliberate rate. May be sitting or walking but activity does not involve physical exertion. Examples: finger painting, block playing, car rolling, clapping hands.
- d. High: Child expends much energy is very active in moving around.

7. MOBILITY IN SPACE

This variable permits ratings on the mobility level of the child. The typical mobility mode or basic posture of the child during the observation period is rated. The levels available for rating are: prone, sitting, crawling-creeping, standing, walking supported, walking unsupported, running-climbing. The categories are self-defining. The last category includes all skilled, independently carried out motor activities, such as jumping.

8. SELF DIRECTION

Ratings on this variable reflect the extent to which the child determines what he wishes to do and pursues that course.

- a. Low: Evidences little interest in activity or involvement. Child may involuntarily respond to environment but shows little curiosity in surroundings or what is being done to him. Passive behavior indication a disinterest in surroundings may perform what is required, but only under constant supervision and encouragement. Little activity when alone. Does not originate much independent action.

b. Medium: Evidences some interest in and performs activity. Is cooperative and indicates some concern regarding what he is doing or what is happening to him. There is some volition in how the physical environment and/or people act upon him. Will reach out for a short period of time without constant supervision or encouragement.

c. High: Child determines and attempts to follow his own course of action. Knows what he wants and does not want. Makes deliberate and sustained attempt to accomplish his objectives, even if in conflict with other person's goals for him. May actively cooperate with others but does not relinquish his own volition in determining his behavior. Is not passive. Evidences high interest, alertness, and curiosity. He makes things happen. Highly explorative behavior. Sustained pursuit of purposive activity (non-repetitious).

9. COGNITIVE BEHAVIOR

This is concerned with the child's mental processes. The observer estimates the typical mental level at which the child is functioning during the reporting period.

Meaningless Behavior

a. None: No evidence of any mental activity.

b. Repetitive: Preservation. Repeated, stylized movements. Finger flicking, rocking.

c. Aimless, random: Non-repetitive but essentially meaningless movement. Lack of contact with environment.

d. Exploratory -- non-directive: Child is in contact with environment in meaningful way. Examines, looks at, explores, manipulates to find out about surroundings. Responds to stimulation offered him. Sensory intake. Child does not have a specific goal.

e. Purposive, goal directed: Child shows evidence of having a goal in mind by his activity. Follows simple directions. Acts to meet a need. Simple combinations of objects or acts to achieve purpose.

Meaningful Behavior -- Higher Levels

f. Experimental: Child uses mental processes to look for new combinations, new ways of doing things, making things happen. Child attempts to figure out how things work.

g. Problem solving -- imitation: Child uses mental processes to solve simple cognitive problems. Child imitates others either directly or in representational play.

10. EXPRESSIVE COMMUNICATION

If a child attempts to communicate to another person during the time period, one of the following categories is checked, according to the type of expressive communication employed. Unlike other variables in this observational instrument which require that the behavior persist for a majority of the time period, a rating is made in "expressive communication" area if the behavior occurs only ONCE. To qualify as an "expressive communication" it must be clear that the child is trying to "tell" something to another person.

a. None: Where there is no attempt to communicate with another person. Whining and crying, without other behaviors, are rated "None."

b. Physical: Where a child is pulling, pushing, tugging, in an attempt to communicate his desires to another person. Examples: Leading adult to the door, handing adult his coat as a means of communication that he wants to go. Distinction must be made between a non-communicative behavior and a communicative one. For instance, a child going to the door and trying to turn the handle is not considered "physical communication" unless he attempts to draw another's attention to his desire for help.

c. Voice Projection: Where a child makes vocal noises in an attempt to "tell" something to another person. Random vocalizations do not qualify here unless there is evidence that they are intended as a means of communication with others.

d. Gestures: Where a child points, signals, or otherwise calls the adult's attention to what he wants or does not want through the use of body movements. This category is distinguished from "Physical" in that here the child does not come into direct physical contact with the object or person but indicates his wants through space.

e. Speech: Where a child indicates his desires or wants by using verbal communication.

11. EFFECT

This category provides ratings on the degree of effect the child exhibits during a time period. There are basically four categories scaled from Anger to Happiness. The "None, Inappropriate" category is reserved for rating where it is impossible to make a rating within the four basic categories.

a. Anger, protests: Where a child is intensely upset, angered, or unhappy. May be accompanied by yelling, kicking, screaming, absolute refusal to continue activity, etc.

b. Unhappiness, cries: Where a child is not enjoying the activity, is mildly annoyed by what is going on, is bored with activity, tries to remove himself. This category is characterized by displeasure or discomfort.

c. Mild Happiness: Where a child is interested in what is happening, is enjoying an activity, or is pleasantly content with what he is doing. May or may not be accompanied by smiles or laughter.

d. Happiness: Where a child is intensely involved and enjoying an activity. Smiles, laughs, squeals. Evidence of great happiness in whatever he is doing.

e. None, Inappropriate: This category is used only where there is a marked lack of any effectual response on the part of the child. Characterized by "stone-faced" look in which the child has no apparent feeling regarding the activity in which he is engaged. Also, this category is used when a child indicated an "inappropriate" or over-response to an activity.

Audiologic Assessment of Deaf-Blind Babies

(Paper presented by Adeline McClatchie on March 17, 1973)
Speech and Hearing Center, Children's Hospital Medical Center
Oakland, California

Approximately twenty such children have been seen in the past year by this Center. Of this twenty, seventeen have fallen in the age range of 0-3 years. The babies are normally referred by a physician and in eight of the cases cataracts had already been removed by the time the baby was seen for audiological assessment. In the case of eight apparent rubella babies, although seen at 8 months to 12 months, they were already categorized as deaf-blind babies. Other etiologies contributing to this population appear to Rh-incompatibility (2), meningitis (1), prematurity (1) and one child born with multiple congenital problems.

Only two of these children have fallen into the category of severe-to-profoundly deaf. Three of the children have question marks over actual hearing acuity despite consistent testing because of their inconsistency in awareness of sound. In two of these cases, rubella has not been verified as suspected. Prior to 1972, these children were seen at our Center and on being diagnosed as having hearing impairments were accepted into a program of visitation twice weekly at the hospital until such time as an educational establishment opened its doors to them on turning three years. With the new educational facility of 18 months to three years for these children, few of them are being pursued at Centers such as ours, unless of course they are under 18 months. In audiological testing very similar techniques are used to those described very clearly and simply in a paper given by Bernstein and Roeser at the American Speech and Hearing Association convention in 1972. Because this paper outlines each of the test types quite specifically, I do not intend to spend much time describing the types of test used but rather refer you to that paper. Formal and informal type testing are used. Where possible, we will condition a child to conventional audiometric techniques. Because we are speaking about children of 0-3 years today, this population does not often apply itself readily to this technique. Play audiometry is used where possible, but we find our most useful form of audiometry is possible conditioned orientation response audiometry. On dimming our test suite lights we find that large, lighted animal to either side of the child is in fact a sufficient reward stimulus. We often further reinforce the light finding technique by using an oral reward also.

This is in the form of the lighted animal putting forth a raisin or cereal or some such goodie on being identified as the sound source. Despite the fact that many people still suspect that small children cannot be tested in head phones, we do not find this a particularly terrifying experience for most babies. We use bone conduction stimuli and record our responses in a similar manner where possible.

On the occasions when COR audiometry is not an adequate form of testing, we often will establish a sound/stroking/oral reward situation. In this form of testing, sound is initially associated to the side of the sound while the child is stroked, and on rooting toward that side, the child is awarded instantly with an oral reward. On many occasions this has been found very useful indeed. On occasions when we are unable to acquire pure tone results we will resort to even more primitive forms of testing. This is a modification form of our standard screening procedure for children 7-12 months. It is basically a modification of the Ewing-Harding method of screening babies for normal hearing acuity. The noisemakers which we use have not just been picked up at random, but rather have been chosen after laboratory testing to identify their major sound source in specific narrow band areas. One rattle has characteristics of a high frequency band of approximately 75 cycles wide at 3000 Hz. Another is primarily located at 500 Hz with a band of approximately 70 cycles. And again a bell is identified at primarily 1000 Hz with very little overtones even of a small variety at other frequencies. Added to this we use pure tone pitch pipes 250-4000 Hz which again have limited use because pure tones continue to be uninteresting. Sound intensity is measured in this form of testing using a sound level meter. Very often when no results are being acquired from pure tones, certain responses can be acquired and identified with this particular form of testing and given a particular intensity identification. We do not accept this as test results but we do accept it as an indication of approximate hearing level.

The acoustic impedance bridge has been of particular value to us in pediatric audiology. In cases where sophistication limits the establishing of masked bone conduction thresholds and even when thresholds acquired are somewhat suspect, this piece of equipment can help determine the condition of the middle ear mechanism. Basically what it does is measure the movement of the drum under pressure changes. This middle ear cavity can be changed by putting pressure against the drum, pushing it inward and gradually relieving pressure and taking readings at various portions along this change. The degree of compliance of the drum is indicative of certain middle ear pathologies and the degree of their progress. This piece of instrumentation has been particularly useful in identifying middle ear conditions which are superimposed on an already present sensorineural hearing loss. It has also been most helpful in identifying a moderate sensorineural hearing loss from a conductive hearing loss. Particularly in the difficult to test young child who is unable to indicate existing differences in bone and air conduction. It has further application in helping to assess the type of amplification best suited to a child's needs when he is able to give

only limited information regarding his actual hearing loss. By being able to measure stapedius muscle reflex, we are able to find indications of recruitment problems. The literature indicates that rubella babies have a high tendency toward recruitment but we are unable at this early age to use sophisticated audiometric testing to pursue this phenomenon. On identifying the possibility of recruitment we are most certain to give the child amplification with a reduced maximum power output enabling him to better use the gain available.

With many babies who are difficult to test because of inherent problems such as mental retardation or deaf-blindness or some such syndrome, we find with those children, particularly those 18 months and under that we have to resort to behavioral observation audiometry. I personally find that this is an acquired art rather than a learned skill. The observer has to be careful that he is not inferring types of responses on the child because he wished the child to pass this test. On the other hand, many behavioral changes are slight and can only be picked up by an astute observer through his experience and working knowledge of child behavior. The most obvious responses during this type of testing: a) arrest of activity which may include ceasing to suck, cessation of crying, sharp intake of breath, b) a primary rooting behavior; this behavior usually is a very slight change of head position to the sound source, c) changes in breathing patterns which can include a change from slow rhythmical breathing pattern to a panting rhythm or in contrast a quick drawing in of breath or slow release, d) wide-eyed look or a startled response where rigidity of parts of the body may be observed.

We are continually surprised that our observations made at early stages and intensity arrived at regarding hearing level usually approximates genuine thresholds by 5-10 dB which have been later clarified by more sophisticated testing.

Amplification is usually placed in the most receptive ear for approximately 6 months while observations are ongoing both at home and at the clinic. The second hearing aid is applied when the first hearing aid is obviously tolerated and there is no obvious acceptance problem. We find that in the occasional case when we fit two hearing aids at the same time that when problems do arise in regard to rejection, it is more difficult to trace the source of that rejection than when we apply them systematically. We are also taking into consideration here theoreticians among whom is Eisenson who suggests that brain damaged children who do require amplification, have more difficulty relating to bilateral amplification because of their central problems.

Post-auricle amplification appears to have become very popular with the group of deaf-blind babies that we have been seeing. I do not believe that we under-fit in way of gain our children's needs, but we are finding in the population that we have seen that children are inclined to fall in the category of severely hard of hearing rather than profoundly deaf. This brief summary of evaluations and

initial care of the children I have pursued in order to give a lead into the reasons and the purpose of our type of auditory training. For further information concerning audiological assessment of deaf-blind children, particularly at this age level, I would refer you to Bernstein and Roeser's report at the ASHA convention in San Francisco in 1972. I find many of their findings and auditory techniques similar to those pursued at our Center.

Our primary goal at the clinic is preparation for a school program of mother and child and cementing together a relationship which has to last a lifetime. In my particular role of encouraging early adaptation to audition, it is important that we observe for super-imposed middle ear conditions which prevent a child from adapting to his hearing aids as he might do and will eventually become accustomed to these things which hang in his ears and their effect. Our role as you can imagine is heavily weighted toward parent counseling and home training and toward the emotional recognition of the stress which this sort of condition can bring into our lives. As school programs become more inclusive of all ages of children, our role as auditory trainers or therapists become less and less, our children of 18 months are now going into the school programs. I've found that if I start off with developing mother love and channeling it toward audition I acquire much better results. I've found it very important to keep terms like "auditory training" out of my work with the parents as these terms can become very confusing to the mother and to her particular role with the child. I try to help the mother see her role as mother, as meaningful and natural and if she can do this it allows every one in the baby's environment to do their own role and no one feels a heavy responsibility. I feel if we can make a good job of selling the role of mother to a possibly disenchanted mother and make her see where she can really get her kicks, we are establishing a foundation stone on which to build a possible education for the deaf-blind child.

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The Rubella Child: An Ophthalmologic View

Jerry F. Donin, M. D.

In the past year, I have been examining the eyes of pupils at the East San Gabriel Valley School for Multi-Handicapped Children. During my regular visits there, I have observed the efforts of the teachers working with these children, or should I say struggling with these children. My admiration for teachers of the deaf-blind, always high, has increased since by geometric progression. Certain key words immediately come to mind - on the one hand, frustration, uncertainty, disappointment - on the other, patience and, above all, hope. I confess some passing feelings of guilt - my sessions at the school have been brief, my contributions concrete and circumscribed, my chores completed with a dictated descriptive note and appropriate recommendations. I am only too well aware that after I leave, the difficult job of attempting to educate these children goes painfully and ever so slowly - on and on. The end is never in sight.

Soon after I began to examine these partially deaf-blind children, it became apparent to me that many, if not most, were suffering the effects of congenital rubella or German measles. As you may know, the great epidemic of 1964-1965, the largest of its kind in the U.S. in the last 20 years, resulted in the births of many children so affected. If current mass immunization efforts continue to fall short of their goals, more children with these abnormalities will continue to be born. For teachers of the deaf-blind, the child with the congenital rubella syndrome will continue to be a familiar sight and to confront you with one of your most difficult challenges.

It is always helpful to know something of the nature of the abnormalities that beset many of your students. This afternoon, I'd like to tell you about some of the eye abnormalities of the congenital rubella child - what goes wrong, if and how it can be improved (you will note I did not say "corrected"), and what the implications are in regard to the child's future development and education.

First, some historical perspective

For centuries, the nature and significance of congenital deformities remained a matter of superstition, religion and folklore. For example, parental impressions at the time of conception, or maternal impressions during pregnancy, were held to determine perfection or

defects in the progeny, while a fright or a calamity was widely assumed to be a common cause of malformations in the infant. Ocular deformities are always obvious, and the fear of the Evil Eye has become deeply ingrained in the minds of many peoples. Such beliefs were not confined to the ignorant and superstitious. Leonardo da Vinci accepted as acknowledged fact that maternal and paternal thoughts at conception shaped the child. Ambroise Pare, a great French surgeon (1573), included a wayward maternal imagination among his 13 causes of congenital deformities and asserted it could not be effective 42 days following conception, since by then the fetus was fully formed and could not be altered by external impressions. In the 16th century, Montaigne wrote, "We know by experience that women impart the marks of their fancy on the children they carry in their womb." This view was widespread in the medical literature throughout the 17th and 18th centuries. As late as 1889, one author (Keating: *Cyclopedia of Diseases of Children*) listed 90 instances of such defects in children.

The first to view the problem of congenital deformities in the spirit of modern rationalism was William Harvey (1651), the discoverer of the circulation of the blood. Applying his genius for the factual explanation of natural phenomena, Harvey suggested that congenital deformities arose as an arrest of development at a particular stage. It was not until 250 years had passed that this logical view began to be generally accepted. With the development of experimental embryology and genetics, there emerged the new science of teratology, the study of congenital deformities. At the turn of this century, it was demonstrated that mechanical manipulation and chemical influences could produce aberrations in development. In 1930, one investigator demonstrated, for example, that a maternal deficiency of Vitamin A in pigs could result in the production of anophthalmos and microphthalmos in the litter. Many similar studies followed.

A major milestone in this field was the announcement in 1941 by Norman Gregg, an Australian ophthalmologist, that rubella contracted during the first 3 months of pregnancy could lead to the occurrence of congenital cataract, deafness, anomalies of the heart and C.N.S. of the child. The importance of this discovery was enormous; it was the first proof of the action of an environmental agent in man - also, it disproved the validity of the general belief that such complex congenital abnormalities could only be due to "faulty germ plasm".

Gregg's inspired observations and conclusions were rapidly confirmed by his Australian colleagues and others. It was initially thought that the risk of the occurrence of multiple anomalies if the mother contracted rubella during the first 3 months of pregnancy was about 90%. As a result, many brides-to-be all over the world were made to contract rubella on the eve of marriage, or hundreds of mothers-to-be, who had contracted the disease at the dangerous period of pregnancy, were aborted. More recent studies undertaken in many countries wherein the infection was specifically diagnosed early in the pregnancy have reduced the probable risk to between 5 and 20%.

Rubella (German measles) as an acquired infection in children or adults is a benign condition. There are mild constitutional symptoms, a rash similar to mild measles and enlarged lymph nodes in the neck. The disease is caused by a virus. The incubation period of the infection is 2-3 weeks. A single attack renders the patient immune for life.

Rubella as an intra-uterine infection may be a total horror by comparison. The virus arrives before the fetus has developed an immune defense; the virus enters the cells and becomes incorporated into them. The virus may remain active in the cells for a period of 18 months or more after birth. The abnormalities that may occur in the developing eyes are:

1. microphthalmos
2. cataract
3. corneal opacities
4. strabismus and nystagmus
5. congenital glaucoma
6. retinopathy

It is during the 5th or 6th week of the pregnancy that the lens of the eye is particularly vulnerable to the invasion by the virus.

Either one or both eyes may be affected.

The first slide represents a schematic cross section of the human eye.

Emphasize the following points:

1. nature of cataract
2. nature of congenital glaucoma

Discuss:

1. nature and significance of congenital nystagmus
2. monocular vs. binocular cataracts
3. the problems of cataract extraction in the infant vs. the adult
4. the importance of corrective lenses after cataract surgery.
5. the importance of early surgery
6. the generally bad visual results (20/200 may be considered a good functional result)

Additional descriptive slides:

1. microphthalmos
2. cataract
3. strabismus

This last slide is a diagram of the entire visual pathway from the eyes in front to the occipital lobe behind (brief general description).

Since rubella may produce C.N.S. disease, the visual pathway may

be affected anywhere along its course and may be still another cause of reduced vision.

When vision is improved by surgery, what does that improved vision mean to the child and to his future development? A child with bad eyes and a good brain may do wonders. A child with good eyes and a bad brain may not. The process of development requires a constant integration of many stimuli via the various senses. Visual stimuli are among the most important - if not the most important. All the ophthalmologist can do is help provide the sharpest visual impulses possible. Once this is accomplished, the child is turned over to the deaf-blind teacher. Now the course to be followed is generally an uncharted one. Results achieved will depend on the efficiency of the child's basic equipment, and the ingenuity and efforts of the deaf-blind teacher.

Show movie on surgery of congenital cataracts.

What Do You See?

Eileen Jackson, Ed.D.®

"What do you see?" Let's explore together some of the processes involved in what just happened when I showed you a glass.



The first, of course, was seeing the object, the final was saying, "a glass". But what happened in between? Something went on in the brain. We can't look inside the brain, but we can surmise that a visual concept of a glass is already there. Obviously this isn't the only glass you have seen; maybe until this moment you haven't seen a glass exactly like this. Once the glass is seen and recognized, a further connection must be made between the object and its name. Thus there must be an auditory memory of a word you have often heard in connection with this object somewhere in the brain. Once we have associated the visual image with the auditory memory of a word, the muscles controlling the movements necessary to say the word "glass" must be alerted. The process is by no means this simple; we actually know very little about how the brain works. The process of acquiring a language is infinitely complex, yet we learn our language at a time when our intellectual growth is not very sophisticated. None of us learned our language for the sheer pleasure of learning. We learned it (1) because it got us what we wanted, (2) because we could control our environment by using it (think of the power of the word no!) and (3) because we had ideas that we wanted to express.

Language isn't merely vocabulary. If I say the word trunk you do not understand whether I am thinking about a trunk full of clothes, an elephant's trunk, the trunk of a tree, or the trunk of the body. Furthermore, I've really communicated no idea about the trunk. Even after the deaf child has learned the names of the parts of the body, the colors, and the numbers up to five, he still can't express ideas or feelings that he may have.

Single words seldom express ideas. However, when a child first learns to speak he often uses a single word as if it were an entire sentence, with sentence intonation. i.e., "See!" Adults seldom limit their

vocabulary to a single word even in talking to an infant. We may rightly conclude that the natural means of learning one's language is by hearing it in meaning-bearing phrases or sentences, and finally intuitively understanding the meaning of the single words involved. Children who can't hear obviously are going to have problems in learning language which the hearing child does so effortlessly. Hearing impaired children have problems of input. It has been estimated that a normally hearing child spends 80% of his waking hours speaking, babbling or listening -- about three (3) million words a year. Thus before he said his first word he had over 3,000,000 exposures to words. (van Uden, 1972, p. 93).

It is important to keep in mind that reduced input of language is one of the major problems of deafness. Because input is so important, every action of the deaf child must be accompanied by appropriate language. As the child is being dressed the following conversation could take place. "Here's your shirt. Let's put it on. This arm goes in this sleeve. This arm goes in this sleeve. Pull it on. Now let's button your shirt. There are five buttons - one, two, three, four, five. Let's button the first one."

Other major problems are (1) the deaf child cannot hear himself. He cannot monitor his own voice through hearing. (2) Since language is the social milieu through which we communicate to others and to ourselves frequently, the absence of language isolates him from others, and finally (3) since most of what we learn at school is done through language the deaf child is at a disadvantage in an educational sense.

Recently a report was sent to me about the findings of a project in teaching language. There was a list of ten words that had been taught through the use of operant conditioning to a group of deaf-blind children. Under the circumstances I would have been impressed with any method yielding such results until I looked at this list: the, I, is, were three words that I recall. In terms of language these words have very little value; they do not express ideas; they cannot help the child control his environment; nor can they help the child get what he wants.

The more restricted the input may be, the more important choices parents and teachers must make. Some of the mileage words might be "more", "help me", "up", "on", "open", "push", "no".... The child must be observed carefully to find out what seems to be important to him. If he likes to be picked up, "up" can give him some control of his environment. There are times each day he may want assistance, "help me"; he might like to be pushed in a swing, in a wagon, on a tricycle, "push".

There are various schools of thought about restricting language if the child has language learning problems beyond deafness alone. Some believe that only single words or even single sounds should be used in talking to these children. Thus the child is exposed to a vocabulary composed mostly of nouns - and nouns aren't language. It is my opinion that for receptive (received) language larger units than the single word should be used in natural situations. However, one can

stress the single word that hopefully the child will someday use, i.e., in the situation where the child indicates that he wants more, you might say, "More. You want more ice cream? I'll give you just a little more."

If language is to develop, it must be important to the child. It must give him results. In this respect, perhaps "no" is one of the most important words.

Auditory Function and the Deaf-Blind Child
 Institute for Parents of Deaf-Blind Children
 Barbara Franklin, Ph.D.

Anatomy and Physiology of the Auditory System

Air consists of infinitely small particles, over 400 billion billion per cubic inch. When we speak, the sound as it leaves the lips sets up a disturbance in the air. The particles bang against each other, without leaving their own position, and the sound energy leaving the speaker's lips is thus carried as a wave through the air to the ear of the listener. The function of the outer ear -- the pinna and canal -- is to collect this acoustic energy. The eardrum thus vibrates with the sound wave, changing the acoustic energy into mechanical energy. The mechanical energy is transferred from the eardrum to the oval window along the three bones (ossicles) of the middle ear. The middle ear performs its main function by increasing this energy through a lever action of the ossicles. As a result, the pressure at the oval window is approximately 35 times more intense than if the bones were missing or not functioning properly (as in otosclerosis). The eardrum also protects the inner ear since very intense sounds will cause a contraction of the stapedius muscle (stapedius reflex) in the middle ear. This reflex action stiffens the eardrum and ossicular chain thereby reducing the efficiency of the middle ear to transmit sound. This muscle, unfortunately, does not work instantaneously, and thus a sudden very intense sound such as a gun shot can cause damage to the ear. The movement of the oval window is transmitted through the fluid of the snail-shaped inner ear (cochlea) to the Organ of Corti which extends the length of the $3\frac{1}{2}$ coils of the cochlea.

If the cochlea were unrolled, one would see four rows of hair cells, resembling bristles of a toothbrush. These hair cells (auditory nerve endings) lie along the basilar membrane within the Organ of Corti. Bending of the hair cells by the fluid movement within the inner ear causes an electro-chemical discharge, thus changing the mechanical energy into nervous energy. All the hair cells are tuned to respond optimally to different frequencies, those closest to the oval window responding to high frequencies and those within the innermost coil responding to low frequencies. These nerve endings are laid out logarithmically, with half the length of the basilar membrane responding to those frequencies below 2000cps, and the other half responding from approximately 2000 - 20,000 cps. Thus the majority of hair cells are sensitive to those frequencies necessary to receive speech. Frequency is therefore related to the place of maximum

stimulation of the basilar membrane, and intensity is related to the number of hair cells stimulated. As the sound wave increases in intensity, more hair cells are stimulated. In addition, there is an increase in the number of nervous impulses per second sent up the auditory nerve. Frequency is measured in cycles/second (cps or Hz), and intensity is measured in decibels (dB). Zero dB refers to a sound which is just barely audible. Since the decibel is a logarithmic scale, a sound of 130 dB is often painful since it is 10 million million times more intense than a sound of 0 dB.

Since the low-frequency sound waves must travel over the entire basilar membrane before it arrives at the low-frequency end, there can be "masking" of the high frequencies by the low-frequency sounds. However, the high frequencies travel only a short distance from the oval window, never reaching the tip of the cochlea. Thus the high frequencies cannot "mask" the low-frequency sounds. "Masking can be explained as a "line-busy" effect. If the hair cells which respond to high frequencies are busy responding to a low-frequency sound, a high-frequency sound won't be able to get through.

The hair cells on the basilar membrane in the right ear connect to nerve fibers which join together in a bundle to form the right branch of the auditory nerve, and the nerve fibers connecting to the hair cells in the left ear join together in a bundle to form the left branch of the auditory nerve. There are four major connections to be made by the auditory nerve as it travels through the brain to its final destination in the auditory cortex. All the fibers enter the Cochlear Nuclei in the Medulla, the fibers from the right ear arrive at the Cochlear Nucleus on the right side of the brain, while those from the left ear arrive at the left Cochlear Nucleus. Damage to either Nucleus at this level in the brain will cause a complete break in the auditory pathway from its associated ear and no auditory stimuli from that ear will arrive at the cortex. The auditory nerve fibers then continue to another area of the Medulla--the Superior Olivary Complex. However, approximately $\frac{2}{3}$ of the fibers from the right Nucleus cross to the left Olive, and $\frac{2}{3}$ from the left Nucleus cross to the right Olive. The remaining $\frac{1}{3}$ continue from each Nucleus to the Olive on the same side. One can see that if damage occurs at the Olive level, auditory stimuli from both ears can still arrive at the cortex if only one Olive is involved. It is important to note that there is binaural stimulation at this level, since auditory nerve fibers from both ears connect in the Superior Olivary Complex. This bundle of nerve fibers, $\frac{2}{3}$ of which come from the opposite ear, now travel to the Inferior Colliculus in the Mid-brain. The nerves connect (synapse) and continue to the Medial Geniculate body located in the Thalamus.

The two branches of the auditory nerve leave the Thalamus and arrive at their destination--the Fissure of Sylvius in the auditory cortex in the temporal lobe. It is in the auditory cortex that hearing occurs. The auditory nerve makes connections with other sensory areas of the cortex, and these associations enable meaning to be ascribed to the sounds. Frequency is interpreted as pitch, and intensity is interpreted as loudness.

Some Interesting New Discoveries in Audition

1. There are several other pathways which can modify the auditory function. The Olivocochlear bundle (OCB) arises in the Medulla and has been traced all the way to the hair cells in the cochlea. Experiments have demonstrated that this efferent auditory pathway can interfere with auditory stimuli arising at the hair cells. In other words, certain sounds can be inhibited or cancelled out before they ever arrive at the auditory nerve.

The reticular alerting system (RAS) is an independent nervous system which deals with attention. This system enables a mother to be awakened out of a deep sleep by her baby's crying. The RAS is involved in attending to auditory stimuli.

2. Some auditory nerves in the brain fire only to binaural stimulation.
3. Normal-hearing individuals hear speech better with the right ear, and music better with the left ear.
4. Dr. John Gaeth is credited with the discovery of a phenomenon which he called "phonemic regression". There are many older individuals who have normal pure-tone audiograms, but poor speech discrimination scores. Few nerve fibers are required to carry pure-tone information along the auditory pathway. Speech, however, is much more complicated, and requires far more intact nerve fibers.
5. Many researchers have found that speech reception scores among the deaf improve up to 15% when audition is added to lip-reading alone scores. Dr. Norman Erber of Central Institute for the Deaf in St. Louis conducted a rather interesting experiment. He took low-frequency white noise with a cut-off at 2000 cps and shaped it in time and intensity to match speech. The noise was unintelligible except for maintaining the rhythm of the lip-read words. Normal-hearing children and adults demonstrated an average improvement of 6 - 8% in lip-reading alone scores when this shaped white noise was added. Profoundly deaf children of 14 - 15 years of age showed an average improvement of 7% when the shaped white noise was added to lip-reading alone.

Gault in 1928 found similar improvements when acoustic stimuli were presented to lipreaders' hands through a vibrator. He hypothesized, as did many researchers that followed, that vibro-tactile, rather than auditory responses are stimulated in deaf ears by acoustic stimuli. It seems appropriate at this point to include the cutaneous research being conducted at Princeton. These experiments include the learning by normal subjects of an alphabet which has been transcribed into a vibration code. The vibrations differ in time -- long or short -- and intensity -- low, medium or high. These vibrations are transmitted by five vibrators which have been placed on certain sensitive areas of the body.

Suggestions to Parents of Deaf-Blind Children

Early hearing-aid fitting is essential. Audition is too complicated and individualized to be able to determine how a particular deaf-blind child hears on the basis of an audiogram. Hearing aids should not be evaluated in a sound-proof room. The prescription should be made by observing the child's responses in his environment when wearing different aids. A mild-gain hearing aid is preferred for questionable cases. Sometimes the only basis for the recommendation of a hearing aid is that the child functions better when wearing one. There is little evidence that hearing aids can cause damage to the ear.

Mobility is improved by the ability to localize, and only binaural hearing aids will enable a deaf-blind child to locate a sound in space. Auditory fatigue is reduced since less gain (volume) is required when wearing two aids. It is hard to imagine how binaural aids can confuse the child since the auditory system is already complicated with nerves crossing from one side of the brain and back again.

For the majority of deaf-blind children, low-frequency response hearing aids are desirable since most residual hearing is usually in the low frequencies. In addition, low-frequency aids take advantage of vibration cues. A hearing aid is indicated if only to tune in to the environment, so that the deaf-blind child knows he is alive and exists. There is often the possibility of the low frequencies masking the high frequencies. The writer has successfully solved this problem with some children by cutting the low frequencies out of one hearing aid, but leaving the low and high frequencies in the other hearing aid. The rationale for this refers back to the section on the "line-busy" effect, since the low frequencies can interfere with the high frequencies, but the high frequencies do not affect the low frequencies.

Every hearing aid purchased should have a B and K analysis made in order to know its exact gain, frequency response, maximum power output, and noise level. These responses can be checked against the specification sheet available from the dealer describing that particular model hearing aid.

Residual Hearing and Auditory Training

Barbara Franklin, Ph.D.

The evaluation of a child's hearing and the training of residual hearing should be considered part of the same process. It is, therefore, essential to use appropriate auditory stimuli and be aware of appropriate responses which will be elicited for each developmental age level.

Up to the age of two months, loud percussion type sounds, 3000 cps. warble tone presented at 80 - 100 dB, and wide bands of noise at high intensities are recommended stimuli. Responses include reflexes, both a Moro response which is a stiffening of the extremities and the aura-palpebral which is the eye blink. Other responses include any change in ongoing behavior, either an increase or decrease of activity, and tensing of the entire body.

From three to six months, soft familiar sounds are most likely to elicit a response. The ongoing background environment is generally noisy, so that the infant ignores loud sounds and is most aware of a change -- namely quiet. The infant is most likely to respond to his own mother's voice. Typical responses at three months of age is an orienting response which is a searching for sound. By four months, the infant turns in the direction of sound and by five months, is able to localize; that is, locate a sound in space.

From seven to twelve months, household sounds are good auditory stimuli in addition to the human voice. The Ewings found a spoon tinkling in a cup very successful in eliciting a response since this signifies food. Paper crinkling and a xylophone are other appropriate auditory stimuli at this age. A spectrographic analysis of the sounds can produce a crude audiogram, since one can determine the acoustic energy of each stimulus. The infant at this age generally responds by localizing sounds in space.

It is essential to remember to present each sound behind the infant to one side of the head, never directly behind the head. One cannot turn to the source of sound when presented in the midplane of the body.

From twelve to twenty-four months, sound toys calibrated on a spectrograph as to acoustic energy can be used. The child will continue to localize. The child's ability to respond appropriately to

simple commands can be added to the assessment of the auditory mechanism at this stage.

From twenty-four to forty-eight months, pure tones and speech can be used. The child can respond with play audiometry -- through operant conditioning, the child is trained, for example, to put a peg in a hole in response to auditory stimuli.

By forty-eight months, conventional testing responses such as hand raising can be used with pure tone audiometry and speech.

Specific auditory training lessons should begin with discrimination of the suprasegmental phonemes such as pitch, rhythm, stress, intonation, and juncture, prior to training discrimination of the segmental phonemes -- vowels and consonants. The rationale for this is that the normal hearing infant derives meaning from these features before actually understanding the meaning of the words themselves. The child should be allowed to look and listen to the teacher as each lesson is introduced. The goal of auditory training is to enable the child to eventually discriminate via the ear alone.

The voiced /b/ (bŭ) can be used for training the child to discriminate the various suprasegmental features:

1. Changes in the number of syllable
For Example: /b/ or /bb/ or /bbb/.
2. Changes in rhythm
For Example: /bb bb/ or /b bbb/ or /bbbb/.
3. Changes in stress
For Example: /Bbb/ or /bBb/ or /BbB/.
4. Changes in pitch
For Example: /b^bb/ or /bb^b/ or /^bbb/.

Discrimination of words should begin with syllable differences, for example: "ball" - one syllable, "baby" - two syllables, and "policeman" - three syllables.

The next step is vowel differences, for example: "boot", and "bat." An understanding of speech formants is essential since auditory training must begin by selecting words containing vowels with very different acoustic energy, and gradually train the child to discriminate vowels very close to their acoustic energy. This training also depends on each child's functional hearing. This cannot always be determined from an audiogram, but requires an ongoing assessment by the teacher of how the child uses his residual hearing.

I recommend the following procedure for auditory training:

1. Present the words alone.
 For Example: "ball" (/ɔ/)

"bird" (/ɛ/)

"beet" (/ē/)
2. Present the words in sentences with the key word at the end.
 For Example: "Give me the ball."
 "See the bird."
 "I like beets."
3. Present the words in sentences with the key word in the middle.
 For Example: "The ball is red."
 "The bird is flying."
 "The beet is good to eat."
4. Talk about the picture, but don't include the key word.
 For Example: "I can bounce it." (ball)
 "It is flying away." (bird)
 "I'm having some for dinner." (beets)

A child's ability to discriminate can often provide more information as to functional hearing than an audiogram. Always remember that an audiogram indicates what a child cannot hear, but a well trained teacher is able to determine what a child can hear.

AUDITORY TESTING FOR THE MULTI-HANDICAPPED

Marilyn Lowell

As a parent for the first time or, even the second or third time, you may not have immediately been aware of your child's hearing loss. Think back to the time you first questioned whether your child was hearing normally. Did your pediatrician notice it, was it the child's grandparents, perhaps a good friend or was it mommy or daddy? Were you immediately cognizant of your child's visual impairment? Often the joy of having a first born or the shock of having a multiply handicapped child clouds our thinking. I'm certain if we called on each of you, we would get many, many different experiences of how your child's hearing loss was first identified.

Perhaps some parents are still in the initial stages of learning a loss is present because a definitive evaluation has not been obtained. You may suspect a loss is present because your child is not talking even though he's more than a year old. You may notice that your favorite music box doesn't seem to attract your child's attention or perhaps your young cowboys and Indians don't seem to awaken the baby from his nap. Whatever reasons you have for questioning the hearing loss, they are bona fide reasons for seeking professional assistance.

Before we discuss hearing testing, let's examine the ear itself so we understand how it works. The ear has three major parts which we will concern ourselves with:

1. The external ear and canal
2. The middle ear
3. The inner ear

The external ear really only serves a cosmetic purpose - to hang glasses on -! Now with contact lenses we don't even need them. Some children are born with an absence of an ear or ears. This really won't effect their hearing if the other parts of the ear are present and functioning. From the

pinna or external ear we have the ear canal which leads to the second part of our hearing system. This canal can sometimes be obstructed by nature, by ear wax or even a berry or bean a child may lodge himself -- all of these can cause some amount of hearing loss but not enough to make a person "deaf".

At the end of the ear canal is the ear drum. This is a very thin membrane which separates the outer ear from the middle ear, our second part. In this chamber are three very minute bones which allow sound transmission. Their names are the malleus, incus and stapes or better known by their alias 'hammer, anvil and stirrup'. Should we add some obstruction here in the middle ear like fluid, we impede or interrupt the flow of sound from outside to the nerves of hearing.

When your child gets an ear infection or your doctor tells you your child's ear drum is reddened, bulging or retracted, we know that inflammation or infection is present in the second chamber. Medication can often clear trouble in this area in a very short period of time and your child will be responding to sounds once again. In some children who have repeated or chronic ear infections, a surgeon will remove the child's adenoids and tonsils and may even do a myringotomy. This involves making a tiny slit in the ear drum to release the fluid, and allow the ear to drain. This will heal itself and allows the ear to recover its formerly healthy state.

The third chamber of our ear is the inner ear. This is the most important portion as here are the nerves of hearing. This area houses the cochlea which receives the sound transmission from the middle ear and stimulates the hair cells and nerves so we get the sensation we call "hearing." Damage can be done to this chamber by ototoxic drugs, high fevers, illness such as meningitis, measles, mumps, blows or falls that result in fractures, old age, maternal illness during pregnancy, rh incompatibility, and some familial conditions. Unfortunately, science has not determined a way to transplant the nerves of hearing. So once the nerve of hearing is damaged the damage is permanent. The amount of damage to the inner ear can vary.

Now your child may already have been examined by an otologist and tested by an audiologist. They've stated your child has nerve deafness, sensori neural deafness or a conductive loss. What does this all mean? Let's go back to the diagram of the ear. Remember there are three parts. If we have a "conductive" loss, this means an obstruction lies in the ear canal or the middle ear and does not allow the sound to travel normally to the nerve of hearing. However, if we bypass the middle ear, the nerve of hearing hears normally. This type, a "conductive" loss can be treated medically or surgically or a person can wear a hearing aid and will hear normally or almost normally.

The "sensorineural" loss or nerve deafness involves the inner ear. The sound is transmitted successfully to the nerve, but due to damage the message is not sent through the nerve to the brain. This area cannot be repaired with surgery. An individual may wear a hearing aid

to help but the sound will not be clarified by the aid, only made louder. It is this type of hearing loss that most of your children will have. With a nerve loss, we need the assistance of specially trained teachers to learn to utilize whatever hearing we may have.

Now you say that's all well and good but how are you going about testing a very small infant or a child who cannot tell us whether he's hearing. We have two types of techniques for testing the hearing of individuals. One group is called "subjective" means and the other is called "objective." The tests are "subjective" in that the person being tested must cooperate by raising his hand, pushing a button or repeating words. The examiner must also make a decision as to whether the person was actually hearing when he raised his hand. This type of test is utilized with adults routinely and young children who are able to follow verbal instructions. For young children two years and older we can teach them a simple task of dropping a block in a box each time they hear a beep. This "conditioning" task is a game for them and requires no comprehension of verbal instructions.

All of the subjective means require participation and cooperation on the part of the child being tested. If he's too small we can make some observations about his behavior following presentation of various sounds. Typically you've seen people startle or jump to loud sounds or you've seen children turn and look for a new or novel noise. The audiologist will make notes such as these when evaluating a young baby. Now if the child is very young, he doesn't look for the sound - or if he doesn't see, he doesn't search for the sound. So we must make judgements about the appropriateness of children's very subtle reactions to sound. Unless a sound is very loud we will not see a startle response. Other reactions we note in testing are:

shift of the eyes

cessation of activity as sucking, crying, playing

changes in rate of activity as increase or decrease in the rate of sucking

beginning of new activity, as crying response

moving toes, fingers, arms

movement of head or body in direction of the sound

arching of the back

kick or swinging of the feet

reaching out of the arm on the side of the stimulus

irritation

pleasure - smiling or cooing

Any and all of these occur during your child's play but a decision need be made about whether it occurred in response to the test stimuli. If the child does not respond to sound, but does respond to visual or tactile stimuli what can we say? Is there another means of testing hearing?

Yes, there are "objective" or relatively "objective" means of evaluating an individual's hearing. Over the years several attempts have been made to devise the perfect infallible technique. At present the most accurate of these means involves use of a computer. The tests are called objective in that the baby need not reply or actively participate and the person testing does not make a judgment as to the appropriateness of the response.

Most of the objective tests have not been successful and are particularly not of assistance in testing very young children and multi-handicapped. One means involved use of shock. For that reason alone we would not want to use it with children.

One particular technique has been satisfactory for use with children. It involves no pain or harm to the child. The procedure is called "auditory evoked response," "cortical audiometry," electric response audiometry, etc. The procedure utilizes a special purpose computer for analysis. A series of electrodes, small disks, are taped to the child's head. The EEG or brain waves of the child are then transmitted through amplifiers to a computer. The child sits quietly in a room accompanied by one or both parents. An auditory signal, (a beep), is presented from a speaker or from earphones worn by the child. If the stimulus was heard, it registers in the brain at a particular time following the signal. The computer averages the brain waves following each stimulus presentation. The sum of these responses then forms a particular waveform when analyzed. Analysis of the results from the computer can then determine the approximate hearing loss level. If a child is too active or uncooperative, sedation can be given. However, we prefer to test the child when he is awake. In testing a group of 129 children every six months, many of them were rubella infants, we found only two who were untestable on one occasion. This test is not readily available in all hearing clinics and is utilized only when audiologists are unable to determine whether a child is hearing or not.

If a hearing loss is found, what does it all mean? You've heard several terms mentioned when your child was tested but you may not understand what they meant. Decibel? Frequency? Intensity? All of these terms are utilized in describing the hearing loss. When we speak of frequency, we are concerned with the sounds necessary for understanding speech that we hear. Frequency is

concerned with cycles per second or "hertz." The normal ear has a range of hearing from 20 cycles to 20,000 cps. However, not all these frequencies are necessary for understanding speech. The telephone company uses a very limited band width and we are able to understand very well over the telephone. So the high and low pitched "beeps" you may have heard when your child was tested were the different "frequencies" important to speech understanding.

Intensity refers to loudness. How loud must a particular sound be before your child gives an indication he is able to hear it? The unit in which we state the amount of intensity or loudness is called the "decibel." This is a unit of measure. For you who might want to think of hearing loss in terms of percentage, you can substitute "%" in place of decibel. So if you've been told your child has an 80 decibel loss in one ear, it might be easiest for you to comprehend as being an 80% loss. Now this is not the exact formula to be followed because hearing impairment is much more complex, but for convenience you may want to do so. There are many other terms which we utilize to describe type and amounts of deafness, but in a sense all of them add information which allows us to understand whether a child will or will not use a hearing aid successfully, will be able to use his hearing to develop speech without special assistance, or will use his hearing to monitor his own speech production, etc.

A hearing aid may or may not have been recommended for your child. What is a hearing aid? A hearing aid is a small device which amplifies sound. Now hearing aids don't have brains, so they increase the loudness of all sounds. We must give hearing aid users assistance in learning to what sounds they must attend. For those of you who have been disappointed that your severely deaf or profoundly deaf child didn't learn to talk as soon as they were given the hearing aid perhaps this analogy will help you. If you were to find yourself in China or Russia, just turning up the volume on the radio would not make the language any more comprehensible to you. You'd have difficulty understanding where one word stopped and the next started unless you were given some tutoring. Just as you, the deaf child or the severely hearing impaired will need assistance to effectively utilize the amplified mumbo-jumbo.

A hearing aid basically consists of a microphone, (the receiver) and the amplifier. We then add a battery, an ear mold and some cord or tube. The microphone is located in the hearing aid and will pick up sound wherever the aid is located on the body - be it the chest, the hair or behind the ear. A tube or cord runs from the unit to the individual's ear. This connects the speaker to the unit which amplifies the sound in the ear.

Hearing aids are temperamental instruments just like other electronic devices. They need the same loving care or they misbehave.

Because they are more sturdy and can withstand a few more knocks and because they can supply more power, we usually suggest the body model of hearing aids for young children. The behind the ear model is not practical for a child who's not stable on his feet. The body aid can be worn in a harness on either the front or back of the child. Some mothers have even devised little pockets to button on the front of clothes and these hold the hearing aid.

The ear mold is important as it's essential to have proper seal in the ear. If the mold is loose, the receiver falls out continually or you may hear a "squeal." We call this 'feedback,' as the amplified sound leads from the speaker and feeds back in the microphone. Ear molds may need to be changed every six months as the child develops and grows in order to avoid feedback. The round button which snaps into your child's ear mold is the receiver. These need be checked periodically as children hide them in the sandbox or get them wet. This may also cause a malfunction.

Another source of trouble is the cord. Due to age or to little children's teeth or tugging, a break may develop in the wires.

If you listen to your child's hearing aid before putting it on him in the morning you'll know if the battery needs replacing, whether the cord is ok and whether the aid sounds clear and is free from intermittent transmission. Periodic servicing at the dealer will also keep it in good running order.

A Parental Guide to the Auditory Training
in the Deaf-Blind Child
"Not So Much a Program--More an Attitude"

Mrs. Adeline McClatchie

My invitation to speak at this workshop hinged on my being practical and demonstrative. It was even suggested that I bring along a child or children for demonstration purposes. I have rejected this suggestion on three grounds. One, that taking the child out of his usual environment can create new behavioral problems which I as the clinician had not previously had to cope with. Two, taking me the clinician out of my usual environment, I may find that my natural exuberance and spontaneity is somewhat hampered. Three, in demonstration it is sometimes very difficult to cover a number of specific points which would normally span a year or so in development with one child at one specific time. So, instead I would like to share with you in another way some ideas and some ways which I find most useful in bridging the gap between being a clinician and yet trying to reach the parents of the deaf-blind child in his home.

The content of this presentation is primarily based on the sensorimotor stages as outlined by Piaget and Inhelder. These stages seem to be the foundation on which to build perception and to develop intellectual skills. They outline developmental steps pursued by a normal child on his way to developing perceptual skills. In my own observations of deaf-blind children I observe arrest or difficulty with these early stages. These stages which develop remarkably smoothly with barely observable transition in the normal infant, are described by Piaget as being "the filtering or modification of input (assimilation) and accommodation, the modification of internal schema to fit reality." Piaget draws out and develops the stages of reflex, the habit stage, the stage of prehension (approximately four and one half months), which seems to be the stage of coordination of vision and prehension, that is grasping and manipulation. The beginning of intellectual pursuits, i.e. objects out of reach, the recognition of one object's relationship to another, and then the sudden comprehension or insight on examining and working out a situation. All of these stages must take place before a child can construct reality and look at it in terms of decentralization, that is separating himself from the mother figure and his own relationship in time and space and causality. The theory of Montessorri as originally conceived and applied to the deprived ghetto Italian child can provide some interesting parallels to the deaf-blind child in our society. When I refer to Montessorri, I make reference to her theory and not necessarily the interpretation of the theory in some of our

teaching methods. For references on physical developmental skills I most often refer to the developmental steps of Illingsworth. With this little theory background I intend now to turn strictly practical.

The knowledge that teachers and clinicians have regarding the development and the needs of the deaf-blind child has sometimes been stifled in our attempts to translate it to the parents of deaf-blind children. Getting started is often the most difficult step in any venture.

Now that the deaf-blind child has been fitted with hearing aids appropriately, for all intents and purposes we are all set and ready to go on training: auditory training, visual training and sense training. However, sometimes in our efforts to start life off best for the baby who has a problem, we overlook or brush to one side the mother and her problems.

"Mothering is something we are presumed endowed with by merely giving birth." Each deaf-blind baby has the right of exposure to both vision and hearing but first we must step back and look at the whole environment in which the child is going to grow up. Let's look at the backdrop. Parents come with different needs and hopes. Sometimes they come singly, sometimes they are in pairs, some are in pairs but singly. Some babies come wanted, some are a burden all through the pregnancy and some I am sorry to say are made to stay with the young mother because she is being punished by her mother for her misdoings. As clinicians and teachers, we are eager to bring help to the impaired child, but we must remember that all efforts are useless unless the people that spend the most time with the child understand and are in unison with some of our goals. I am also respectful of the fact that in every mother there is a person that needs to be considered. We often assume that the mother must be totally responsible for the child and so this sort of picture often emerges (slide 1). For the mother that has to endure that life, at least we can make it easier for her by understanding her needs and making her work more enjoyable. After all, when we think of it we only require that her already existing love is strengthened and channeled. Let's forget for a little while that we are teachers and professionals in any form and let's become mothers. We have just learned that our child has a hearing and a vision problem. Following the initial emotional shock we are now caught up in the need to act and the demands for action and for explanation are all around us. Communication now becomes important. How do you make this child listen? How do you make this child understand? How do you make our child speak? What a task! Mother often finds herself the elected person to take on the very burdensome role of teacher-mother. Teacher to the child, teacher to your husband, teacher to siblings, teacher to the world at large. Your life becomes very changed. You feel resentful of the responsibility and awed by the task. At home grandparents demand explanation, siblings require special favors and attention; husbands need up-to-date information and special understanding.

RELAX; let's take it from the beginning; leave the clinicians to do their clinical work and the teachers their teaching and let's investigate

how best to parent a deaf-blind baby. First let's look at what is basically different between the normal and the deaf-blind baby. It is not intelligence, but rather the motivation to use his intelligence. The normal baby leads us along. We have all heard ourselves say at some time, "Oh, look at what he can do now!", "See, he's trying to crawl!", "Oh, look, he's pulling up!" With our deaf-blind baby we have to anticipate his next step of development and find ways to encourage it to happen. Take heart; remember communication is contagious. Language continues to defy psycholinguists as to its actual acquisition--it appears in child almost by osmosis. Montessori tells us that the child who does not act asks nothing--he says nothing. What are some of the most helpful things we can do with our babies at home? (Slide 2)

Sometimes our baby is content just to lie. He seems happy doing this, at least he doesn't cry. Maybe we haven't given him a reason to move. Isn't crawling normal? Yes, if you can see something to crawl toward or hear something to draw you nearer. As early as possible have close to the baby an object colorful and musical which becomes a love object (slide 3). This can be used as an enticer for all sorts of early activities. Be comfortable moving him holding him firmly. Be decisive but warm in your movements. Make your touch welcome, firm and secure, not light and tickly. Even if he wimpers and resists, help him to stretch out and give him an immediate reward. (The reward can be the love object or a warm love response.) Rolling comes natural to some children, but give him a reason and encouragement to roll. (The little bell in the ear of the love dog, the bright yellow, furry ball.) Make movement fun for you and for him. Keep thinking ahead as to the next step of achievement he can reach. Make each step small and unfrustrating, yet challenging (slide 4). Encourage him to move out and explore. Remember he only knows himself; you must bring the outside to him. Seeing and hearing children have horizons as far as they can see or hear. Deaf-blind babies look to us to provide them with their horizons. Bring objects in; make them familiar. Then gradually move them outward, further and further (slide 5). Lifting. Sudden jolts are startling and create panic. To be moved from one place to another without previous warning can be a really frightening experience. Remember our seeing babies watch the approach and prepare their bodies for upward movement. Hearing children are alerted to our approach and consequently prepare themselves (slide 6). Think ahead, an extra movement to touch and reassure. A cue which becomes the stimulus for getting up can develop a warm dependence on you and help you learn to understand each other (slide 7). What is a mother? She's someone with a tune in her heart and time to spend with you. Rhythm and movement are early naturals. The fun of returning to the womb state rolled snugly in a blanket, secure, warm, and relaxes. From a very early age all babies love movement. Your baby enjoys being thrown up and down and horseplay. If he doesn't yet enjoy that, start him off securely. Don't try to teach him to enjoy the rhythm, somehow or other he'll enjoy it because you do. Get used to singing a lot. Horseplay is good for his body muscles to strengthen and develop them but also for his relationship in space. Observe when he is frightened and use small, firm movements. Teach him to land on a cushion. If he lands on his nose, teach him to

put his hands out to protect his body. As he enjoys more and becomes more secure, make the task larger and further away. Body play is so important at this early age.

(Slide 8) Sound is not the only requisite of listening. Quiet stillness is also equally important. A time to enjoy closeness and warmth, to hear your own body noises.

(Slide 9) Small babies need lots of sleep and quiet!?? Wrong!!! If a baby is quiet he is content! Maybe. An awake baby doing nothing is dying of boredom.

(Slide 10) Let's give him something to enjoy, something to give his vision focus. Something which makes noise when he accidentally hits it with his hand. Something to explore close by which will give him pleasure and will become familiar. Once he starts knowing how to find the ball or how to swing the bell or how to kick the ring, move them and watch him find out all over again. Remember, keep his aids and glasses on all the time, you don't remove your ears and eyes when you go to bed.

(Slide 11) Body exploration is natural and can be easily encouraged and extended. All parts of our bodies can be assigned particular sounds and play activities. Establish patterns of play so that babies then can anticipate parts of the routine. He will begin to recognize voice patterns and anticipate the next activity. Develop little rhymes for repetition in play with different parts of the body.

(Slide 12) Having your toe up close is comfy and belonging, but I wonder when I stretch out where I actually am. Putting a colorful mitten on a foot or on a hand with a little bell is a great visual tracer and encourages both sound and vision to begin distance perception. It gives the idea of length to the baby and his ability to control by contracting or extending the appropriate limb. This leads to more and more exploration of cause and effect. The string tied to a ball can pull a ball. Help your baby to observe the ball a little away, but help him to pull the string in his hand to bring it to him. Accompany the rolling ball with vocal fun noises. Peek-a-boo games are always fun. Put the diaper over your baby's face, pull it away to reveal his colored foot. Let him experiment with this and other objects concealed under a cover, behind a chair, behind a cushion. Let him create effects. A cardboard box with windows (a great game for peek-a-boo). Extend this game forever when he shows an interest. Initially, play this game with sound close by the baby's ear but as he gets used to this game, draw further and further away and watch how he copes with sound at one foot, two feet, three feet distance. Maybe he even can recognize sound above his head.

(Slide 13) Exploration is fun, but sometimes we worry about safety. An anxious mommy gives a feeling of bewilderment to her offspring. Just think for a minute, when you hold a baby on your lap, he makes climbing movements as early as four months. The Harvard baby watchers have observed babies climb to safety before they can sit steadily.

(Slide 14) Let him explore. But cushion his fall. Don't confuse him by denying and encouraging him to do things at the same time. Be ahead of him. Baby-proof his trail, but leave it interesting. This picture is also symbolic of life. Be there to cushion his fall but also to permit his experiencing of a fall. If he doesn't fall, how will he learn how to get up? To many of us mothers the play pen is one of the most important baby features of our home. I wonder how our child perceives it? Play pen or prison? The play pen is only fun when it is voluntarily used as a play pen. Of course there are times when you must use it for safety but most of the time why not pull the side of the play pen down to make it into a climbing area? This can become a little haven or recluse for your child and his play things, from which he can climb out or escape to venture into the world of the living room or the kitchen. By not insisting that he stay in the play pen, you may find that he returns to it more often than you anticipated because this has become his security spot.

(Slide 15) Bath time--a fun time of day. Yet how many unanswered questions. What is water? Is it always in the bathtub? Is it always lukewarm? Don't always feel it necessary to prepare the bath and then put the baby in it. (Slide 16) Let him help in preparation. Leave on his aids and his glasses so he sees and hears the rush of running water. **Wow**, it's cold, and **Ouch**, it's hot. Now I hear it; now I don't. Depending on how much washing is to be done, remove or leave the aids and glasses. The fun of water play can not be overrated. A plastic bowl, a measuring cup, a metal container are set up for hundreds of experiments. Soap smell, bubble blowing, the trickle of water, the splash of the soap, the hard, cold rim of the bathtub, the warm water. This is nature's wonderland.

(Slide 17) What toys should I buy specially for my child? Often parents ask this question. Each toy on the market provides a stimulus source of a limited nature. The ideal noise toys have been given to all of us, although some of us use it less frequently or less selectively than others. The choicest, most tuneful, most varied sounds come from the human voice. Toys are no substitute for voice. They provide variations of sound sources and are useful for experimenting with, but don't forget, no toy can do what you can do. Your voice can be high, low, loud, soft, smooth, staccato, harsh, soothing, rhythmical, and beautiful. It accompanies all interaction and has the right quality for a given moment. Relax and know how each situation has a different use for your voice. Enjoy yourself--sing and laugh, chastise, smile, cough, pant, be silent around your baby. If you can do this naturally, you are off to a good start. A baby will catch your mood and your sound and in his natural way will begin to imitate. Take your baby on walks. If he is still small, don't wheel him. Carry him in a sling close to your body for movement and security. Or on your back for observation. Eyes are much prettier than knees every time. Anticipate your baby's needs, then provide a way for him to get them.

(Slide 18) Next to activity, food is baby's natural desire. If your baby is still not aware of sound through his aid, use this time to teach him that his ears are an important pathway to fulfilling his needs.

Quietly speak to him on one side and even when he shows mild awareness to your presence reward him with food. This way he will learn to root for food and use his hearing to get it. The kitchen is a marvelous experimental ground. Texture, touch, temperament, crunch and chew; they're all in here. Provide him with opportunity to sample everything. Seeing babies usually learn chewing habits by observing other people chew. Sometimes our babies need to be taught to chew. Gently manipulate his jaw while holding the back of his head with the other hand. You can teach him to bite on a piece of watermelon or chew on a piece of bread. For each of these achievements, build in your own reward system. Some children enjoy hand clapping. Some children enjoy an extra hug. You will find out what you and your baby most enjoy. Keep your baby close while doing household chores. Cooking is an experience for everyone. It is also a good nibbling time. Listen to the sound around you. Running water, sizzling bacon, spitting fat, fascinating background noises. Don't drown them out with music. Become aware of them and direct your child's attention to them. This is a marvelous place for language. I find that many children learn food signs faster than any others. Hot, more, milk, Mama, wet, all gone. A natural environment to get natural language in repetition. Move your child's hands in gestures and signs, especially if his vision precludes obvious speech reading patterns. Give him a means of letting you know what he understands and wants even if he can't tell you yet.

(Slide 19) Take baby with you on your house rounds. Let him hear sweeping and cleaning noises. Let him ride the vacuum cleaner. Let him enjoy your little cleaning song. Let him enjoy you. Give him a bowl and a spoon and let him accompany you in song. His squeals of delight will be your reward and your natural way of extending those ee's to longer sounds and more varied sound.

(Slide 20) "Sometimes I just sits and thinks and sometimes I just sits." Sometimes our children sit for a long time rocking and hand-waving, self-occupied. We've been told "try to keep the baby engaged" and we produce toy after toy, and we end up (Slide 21) with a room full of toys and a still preoccupied child. This occupation is often a sign of confusion and need channeling. Guide your child to activities that are fruitful and outreaching. Reintroduce an old favorite toy with a new activity. Dressing a teddy bear, feeding a doll, washing a baby, anything.

(Slide 22) Preoccupation and perseveration on any one activity may indicate that our child is having a problem breaking down his environment into chewable portions. Make stepping stones of reaching out for him. Sometimes a complete change of activity is too difficult for him to cope with. (Slide 23) Try altering his perservative activity. His blocks which he usually bangs together now have been stuck together with tape and require new movement and new procedure to pull them apart. (Slide 24) How difficult it is to turn repetitive investigative activity into something meaningful.

(Slide 25) Join in and make it a listening, repitive activity. Let

him lead the rhythmical pattern and you follow. This can lead to all kinds of vocal and auditory patterning and to important peek-a-boo games. This auditory patterning can also lead in to the recognition of different objects just by the length of their name.

(Slide 26) Child rearing and housekeeping always have conflicted. Sometimes a house becomes more important. Stand back. Look at your house. Is it oriented to child play and freedom of investigation? Can he touch most things that are at his level? Have you followed him around lately letting him feel textures and hard things and large things. Plants can be handled and smelled with respect. Take time to follow your child and permit him exploration. If something must not be touched, put it away or put it up high. Put all those cleaning materials from under the sink in a high cupboard, and out of harm's way. Turn a cupboard in each room into a special area. (Slide 27) A drawer or cupboard in the kitchen with real spoons and plastic bowls and cups can be a long time occupier and a close play area during dinner-making time. Put on the door a bright piece of felt or a drape of bells as the identifier of your child's particular area. This does not protect your other cupboards, but it does turn the negative into an alternative in times of difficulty.

(Slide 28) Out-of-doors in the park is a fun place, but all of us have the fear of a child's getting poisoned, eating the sand, getting hit with the swing, losing his aids, breaking his glasses, etc.

(Slide 29) Give him the same experiences as your other children, but take precautions where possible. Glasses and aids can be held in place by a wire connector along the hair line. Help neighbor children or your own children not to be responsible for but to understand how to play with your child. Let them help him find his way through a tunnel, climb up a slide, to slide down with him. Many kids enjoy this provided it is not considered a responsibility.

(Slide 30) Problem-solving--How to get the water. Don't always rush in to help. Encourage your child to explore possibilities of solutions.

How can you be a "good enough" mother to your deaf-blind child? Remember the importance of routine and repetition. The regular sounds that always accompany particular acts: dressing, bathing, feeding. Recognize his needs and then help him aspire to them. By loving him in this way, you will have provided him with the realization of fun around him and a readiness for a good school program. If you can fit him into your regular schedule and you into his, the other family members will take your example and will follow the leader.

Many of the things I have said are perfectly obvious, but I have found that sometimes the perfectly obvious things are the things that go unsaid and turn out to be not so perfectly obvious after all. It is still important to me that I can achieve steps in sound production and the reception of sounds. The concept on and offness of sound, the ability to associate sounds with objects or with people is still important to me.

In my own work in the clinic I am continually trying to extend the child's parameters in relationship to sound. Once he identifies a sound close up, then by removing it and having him identify it at a distance of three feet. The "what" questions and the "where" questions are extremely important.

A. "What" questions:

Establishing the initial vocabulary of noun reference is probably one of the most difficult things in a child's concept and yet it is most natural to many children. At one time I believed in continual bombardment of language for deaf-blind children. I'm now more inclined ✓ to bombard yes, but to have a specific number of words mostly three to six on which I am actually working to observe response. These initial words usually include, "shoe, more ball, help, jump, milk, and cookie." On this very basic vocabulary (slide 31), simple phrases of what's and where's can become infinite.

B. "Where" questions I find very significant in helping memory:

a. I initially start out by asking the child, "Where's the ball?" while I am presenting the ball to him. When I feel there has been sufficient repetition of this, I put the ball to one side while producing something else, look at something else and then say, "Where's the ball?" My hope is that the child will have delayed memory of where we actually put the ball. After he becomes more astute at this task, the delay is made longer with probably a short activity between the first reference and the second reference to the object, learning to localize. If the child is using bilateral amplification well, he is able to trace sound three feet from his head at least from one ear all the way around to the other ear. Once he is able to do this he'll be able to localize the source of a sound above his head, behind his head, on the floor, etc.

I try to give a child words for an emotion as soon as possible. Angry, sad, happy, mad, smile and tear are important conversational terms used pertinently throughout the therapy session.

"Language" A Comprehensive Approach

Lonna Anderson

PHILOSOPHY

M. Groht states that "Language learning should go on all day in all activities. The child must have understanding before he can use words to communicate. (He will communicate in other ways; such as drawing, pantomime, gestures.)"¹ Alexander Graham Bell is quoted as saying, "Spoken language, I would have used by the pupil from the commencement of his education to the end of it, but spoken language I would not have as a means of communication with the pupil in the earliest stages of education because it is not clear to the eye and it requires a knowledge of language to unravel the ambiguities. In that case, I would have the teacher use written language, and I do not think that manual language (finger spelling) differs from written language excepting in this, that is better and more expeditious."²

With the foregoing taken into consideration and due to the severity and multiplicity of handicaps of deaf-blind rubella children as well as the extreme difficulty of learning to understand speech and express ourselves in speech with defective hearing and vision, it is highly doubtful that many of our children will learn to communicate by oral methods.

LANGUAGE ACQUISITION

In studying communication it has been found that communication has three aspects: 1. inner; 2. receptive; 3. expressive.

Receptive language is acquired through the visual and auditory channels. The visual channels include lip reading and reading. Included in the reading is reading of the written word as well as the signed or the finger spelled word.

Expressive language is exhibited through speech, writing, pantomining, signing, and finger spelling.³

J. Carroll states IX stages of language development that need to be remembered in planning a language program.⁴

1. Stage of exposure
2. Stage of awareness or absorption (receptive)

3. Stage of beginning language comprehension
4. Stage of beginning of symbolic communication
5. Stage of beginning differentiated speech communication
6. Stage of limited expressive units
7. Stage of larger units of expression
8. Stage of connected language
9. Stage of mature language

Unfortunately most parents are not aware of their child's hearing loss until he reaches the stage of beginning language. The first year of education of most deaf children is spent in the stage of exposure and stage of awareness. In the Meadow studies of deaf children who have deaf manual parents, these stages of exposure and awareness are not missed.⁵ The Vernon, Westminster and Koh studies concluded that the reason the deaf child of manual deaf parents achieved higher scores in the area of reading skills and written language was a result of the early manual language exposure. It seems if this is true for the deaf child, it would have greater effect for the multi-handicapped child.⁶

The critical period for language acquisition is between the ages of 1 1/2 and 4 years and declines thereafter. During these years, a child is naturally dependent and is highly motivated to learn.⁷

It should be noted that step 8 is completed by the normal hearing child at approximately 3 1/2 to 4 years of age. By the time the normal hearing child is 8 years of age his ability to use speech sounds is considered adequate.

The children I am committed to are six deaf multi-handicapped 3 to 8 year olds. In addition to deafness the handicaps which exist are: congenital heart defects, involved visual handicaps, cerebral palsy, neurological handicaps, emotional disturbances, cystic fibrosis, and a general low level of development resulting in infantile functions.

PRACTICAL APPLICATION

Unfortunately multi-handicapped children are not admitted to our program until they are 3 years of age. When a child enters our program he may hear but has not learned to use his hearing, he may see but has not learned to use his vision, he may have observed that he has a body but has not learned to manipulate it.

There is no question that when communication is limited, opportunities for learning are also limited. Upon assessing problems of the children in my classroom, it was observed, with the help of Dr. Ronald Hudson O.D.F.F.

A.A.O, (University of Southern California, Staff of Optomology) that the children's vision was such that in many cases lip reading was impossible. In order to involve the entire class, the "Total Approach" was decided upon. (Lip reading, Tadoma - speech - written language, finger spelling, signing and amplification.)⁸ Communication would be a means to an end not an end in itself.

In order to help the children in my classroom acquire straight language we have set up language patterns. Those patterns enable the child to form and build sentences. The language patterns we use were developed by Leahea F. Grammatico, San Francisco State College. The four questions and statements would help the child know what was occurring and give him a basis from which to form his sentences. These questions and sentences seem to take in all the things the pre-school child would want to say. These statements can all be expanded. Questions and Statements are:

1. What happened?
2. Help me.
3. I want that.
4. What do you see?

We found that language did not exist in lists! Language is what you say!

The approach to language at this level because of the involvement of the children is derived from the concrete. Concepts and language are presented at the same time. The teacher provides a need for acquiring language by providing concrete experiences at the child's level of interest.

The learning experiences the first year are ego centered. The children are young enough that they are only concerned with themselves. All vocabulary is taught in sentence form.

N + V

N + V + NP

All oral manual work falls into the following patterns.

I want ____

Where is ____

May I ____

What happened?

What do you see?

How many?

The following word list is the vocabulary to which the children have been exposed.

a	bear	boy	candy
apple	bed	bread	car
all	bicycling	brown	cat
baby	black	break	chair
bed	blue	butter	cheese
banana	boat	butterfly	children
ball	book	buy	Christmas
be	birthday	cake	coat
cold	finger spell	Indian	purple
come	fire	is	rabbit
clean	flag	jump	read
cry	flower	kitchen	restroom
cook	fly	know	red
corn	food	listen	run
cracker	fork	look	sad
cup	funny	man	Santa Claus
dance	get up	make	Saturday
day	ghost	milk	sandwich
doctor	green	mistake	school
die	girl	money	scissors
dishes	glass	Monday	see
dog	glasses	Mother	sell
don't	go	my	shoes
door	good	name	sick
doughnut	goat	napkin	skirt

drive	good-bye	no	soup
drink	grass	on	spider
duck	green	old	stockings
eat	hands	one	stop
egg	happy	orange	soap
elephant	hat	owl	sorry
everyone	he	paint	spoon
Easter	hello	pet	sugar
eyes	hat	pink	sun
face	how	pie	Sunday
fall	I	play	table
family	ice cream	plate	telephone
feet	in	potato	throw away
that	turtle	we	wind
today	TV	Wednesday	woman
tomorrow	ugly	wet	work
thank you	umbrella	who	write
they	up	why	yellow
to	wash	will	you
tree	wagon	was	yesterday
Tuesday	walk	water	

Exposure was presented by experience not by word list. Three of the five children were able to use the "Total" communication method at the end of a three month period with meaning. One child was beginning to use "Total" communication at the end of a nine month period. The fifth child in our first year's program has not used any meaningful communication. We feel this is due to the nature of her multiple handicaps. However she is beginning to recognize speech sounds and will imitate the "P" sound with the use of the Tadoma method.

Teacher, parents, hearing children and all of those in the children's

environment are encouraged to communicate with the deaf using any means that really works.

A finger spelling and sign language course was set up at the high school. The majority of my student's parents participated in the course as did this teacher and the teacher aid. After signing and finger spelling was used in the school, as well as in the home, many of the parents stated that for the first time there was a genuine two-way communication with their child. One of the mothers observed that her child did not beat her head as frequently. Another mother observed that her child used oral communication more frequently.

Oral communication, signing and finger spelling are used at the same time. The Tadoma method is used whenever needed. The overhead projector is used with the combined oral and manual method. While the light attracts all of their attention, the children that have sight are able to read the writing that is projected. Naturally only large letters are used on the overhead. Due to the attraction to the light, I have found it necessary to turn off the light while I am talking.

Acquiring language for the multi-handicapped child is a long involved process. The method I use is as follows: The teacher presents the question or statement to the child. The child is expected to respond. If no response is forthcoming, the teacher will take the child's hand and form the manual response. An oral response is also expected. The teacher may find that she will have to assist in this response too. In most cases the teacher will have to give the child the language expected using the Tadoma method.

Language response may fall into the following pattern.

1. Teacher's statement or question.
2. Child's response (If no response go to next step)
3. Teacher finger spells or signs the child's response.
4. The child copies the teacher's response. (The teacher may have to physically move the child's fingers and sometimes lips too.)
5. The teacher gives the child the oral language in sentence form. (Using the Tadoma method)
6. The child repeats the oral language. (The response may only be the rhythm of what is said depending on the child's ability)
7. The child should attempt to do it by himself without the teacher's assistance.

Music and singing are important parts of the children's day. They have learned to sing and sign some songs.

Individual lesson plans are made for each child. Each child has previously been evaluated in the areas of hearing, sight, motor coordination, language development and mental development. Use of individual lesson plans makes it possible for each child's individual needs to be taken into consideration. It also gives a record of the child's progress regardless of how slow the progress is.

Daily contact is kept with the parent in the form of a "News Book." The daily experience story is included. The experience story is written in kernel sentences at the level of the child.

Example:

Today is Saturday.

Mrs. Anderson went to school.

She talked.

The last school day of each month a list of new vocabulary is sent to the parents. Drawings of unfamiliar signs are included. Parents observe and participate in the program one day each month. This way they have an accurate idea of the progress of their child in the class. The teacher can then help the parent with any problems in communication he is meeting. Another afternoon each month all the parents attend a parent meeting. Each meeting a particular subject is discussed. Example, (What does my child hear?)

SUMMARY

In conclusion the most important things that I have learned in teaching deaf multi-handicapped children are the following:

No single method is adequate. The "Total Approach" is necessary. This includes the use of oral communication, manual communication, Tadoma, written language and amplification.

In order to motivate communication it is of paramount importance that the teacher create experiences at the child's interest level.

In order that all forms of language be a useful tool to the child, the parent must be involved. Because we are involved with these children only a small part of the day, Parent Participation can not be over stressed. It is of utmost importance.

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The Role of Vision in Communication

with Deaf-Blind Children

Anne Galloway

When considering communication with deaf-blind children, we are concerned with the child's hearing and verbalizations, often overlooking the significance of his vision. The five basic roles which vision plays in communication are: to gain information from the environment; to synchronize visual perceptions with other senses; to enhance relationships and understandings with others; to assist imitation; and to receive formalized symbolizations.

The information the child visually receives from his environment will contribute to his concept formation. These concepts will become the foundations for his language development. The understandings of these concepts can be no better than his perceptions. If the information received is distorted, and is not clarified through other senses or additional experiences, it follows that the concept formed on that information will also be distorted - thus, your basis for a language concept and the child's may not be consistent.

The child needs to learn to coordinate his vision with his other senses. If he touches or hears something which is unclear he can use his vision to add the necessary information for clarification and/or localization of the stimulus. Also, working with movement, vision helps the child to direct his body, hands, and feet. It can serve to "tie together" the information received through the combination of the other senses.

Vision is used to enhance the child's relationship and understanding of other people. He needs to be able to "read" the informal body language, facial expressions and gross gestures of others. These non-verbal communications help develop and clarify the feeling of others and define his relationship to them. With more formal systems of communication, he can visually supplement the unheard inflections of the voice and intensify the understanding of what is said. Later he will need to use his vision to discriminate for finger spelling, sign language, and/or lip reading and possibly for some print reading. Much of the child's learning depends on his ability to imitate whether it be for concept development, or skills relating to manual and oral communication.

Consider for a moment the terms relating to the medical and

functional aspects of vision. It is important that you have access to a good medical dictionary and a good working relationship with an ophthalmologist to help you understand each child's individual visual problems and to interpret what the medical information means functionally in terms of his education. The two most common problems seen with the Rubella children are cataracts and nystagmus. Cataracts are, generally speaking, a whiteness or opaqueness of the lens of the eye. Usually by the time the child enters an educational program he has had surgery to remove the cataract and lens and has been supplied with glasses that are quite thick - a man made lens replacement. This condition alone, even after surgery, reduces the child's visual potential. Nystagmus is the involuntary movement of the eyes. There are many types of nystagmus, usually not differentiated in the medical reports. With Rubella children, it is not known to what extent they can learn to control this movement, or compensate for it, so as to be able to attend or focus.

We must also be concerned with the child's visual range and visual field. How far, in any given direction can he see, and how well. If there are any blind spots or areas where the vision is decreased, we must take care to present the desired stimuli in those areas of the field and range which are most functional for the individual. The medical reports we receive usually do not include this information, so you will have to obtain it through observation. This may be accomplished through trial and error = watching where the child moves an object for inspection, if he does so. In a dark room, you can move a light or lighted object toward the child from a variety of angles and distances, observing when and where he apparently becomes aware of them.

There are two terms which are commonly included on vision reports: legally blind and partial sight. These terms are referring to the visual acuity of the child, usually based on information from a Snellen Chart test. Because of the difficulty or impossibility of this type of testing with many Rubella children, the doctor must make an educated guess of the child's visual capacity. This information should be used as a point of reference when observing, with the understanding of the necessity for a crude reading and educated estimate rather than an accurate evaluation of the child's visual capacity.

Many of these children have glasses. I do not know of a successful method to keep the glasses on a child who does not want to wear them. If the child has learned to use his vision, and is able to "see" better with his glasses then I believe that he will keep them on; if he does not use his vision, and is not aware of the difference they make, then he will probably resist wearing them. There are two types of children for whom the struggle is most important - those children who have had cataract surgery and need their man-made lens; and those children who are sensitive to light. With the latter, their glasses are slightly tinted to cut down the glare and they should keep their glasses on whenever they are near any strong light sources.

A final problem is the sunlight - many of the children seem to be drawn to it. I don't know if this is because their pain threshold is

different or if the feeling is stimulating, but this activity can cause irreversible damage. The rays of the sun are burning and can damage their eyes. Their glasses may be intensifying this effect. If the child must shadow play or play with light, direct him to another light source which is nondestructive.

When planning an educational program for a deaf-blind child, we must consider the variation in the individual child's vision. Children with the same medical diagnosis vary in the potential capacity or use for their vision and in the functional use of that potential vision. So each child will need to be considered individually and re-evaluated periodically - medically and educationally. We must also be aware that their predominant sense for learning may not be that sense which is most intact - they may, for example, be a hard-of-hearing and legally blind child attempting to function as a deaf-seeing child. After we have determined what sense or senses, the child prefers, we can train that sense as a major avenue for learning and use it to motivate and reward the training of the other senses.

There are five basic, visual skills that we will consider in the child's program: focusing, tracking, discrimination, and coordination with another sense. Visual attending may be observed when the child has his eyes fixed on a stationary object. This is most difficult to observe with a child who has Nystagmus. I cannot tell you how long it is necessary for a child to attend to an object in order for him to "see" it, as this appears to be an individual trait. Focusing is educationally not easily observable. It is when the child "tunes in" the visual picture of what is being "seen". To help the child attend and focus you can place the object for inspection so that the surrounding visual stimuli are minimal and do not detract from it and/or so that the background is plain and of a contrasting color. Thus if the child is going to "look" there is a greater possibility that the desired stimulus will be the object of that "looking."

Tracking is the child's ability to visually follow an object when in motion. This usually occurs after he can attend to and focus on a stationary object. At this stage you should be aware of the blind spots and/or Nystagmus. You may need to assist the child, or help him compensate by following the tracking with his hands or body. Visual discrimination is when the child can differentiate one visual perception from another. Initially we can assist the child by having the desired object in good contrast to its background and in an uncluttered area. If you hold an object in front of your print shirt, or wear clothes that blend with the walls, the child's discrimination of the object or of your motion is more difficult. Finally, the child will have to learn to coordinate his vision with other sense and with motions. Each coordination will need to be taught separately - eye-hand; listening and reading signs; listening and lip reading; and later listening, moving and reading a visual cue.

As we teach, we need to be aware whether we want to be using a uni-sensory or a multi-sensory approach to an individual task, and control the stimuli accordingly. The dark room is a good way to do this. This does not mean that you have to have a separate dark room - a closet, a large box, or a tent will allow you to sufficiently control the visual stimulation.

You will want to amplify the desired stimulus for the child and de-emphasize unimportant stimuli. We can use light and dark to motivate, maintain and reward attention to a particular stimulus. Awareness begins with the presence and absence of light; then the awareness of a particular light or object in a stationary position; and then the awareness of that object or light source in motion. Later the awareness of light and its source can be used as an assistance to their vision, and to intensify the visual stimulus. Motivation involves the drawing of the child's attention to a particular object, motion or area, and maintain his interest long enough for him to visually gain from the experience. Light as a reward is particularly valuable when attempting to have the child initiate a movement or a sound and when attempting to have the child imitate a particular movement or sound.

The child needs to be aware of the sources of light. He should be able to locate the source then later control it for better functional use of his vision. He may need to take an object to the light or vice versa; or he may need to understand that he cannot read lips or signs when facing the light source.

Auto photic behavior, or shadow play, needs to be used if it is the only self initiated and rewarding behavior of the child. It can be altered from only self stimulating behavior to more meaningful exploration. The movement of raising an object to the eyes is necessary for later meaningful visual exploration of the object. The movement in front of the eyes needs to be slowed down so that the child's perspective or focus is on the object rather than on the shadow created by its motion in front of the light source.

As teachers and aides we need to be concerned with the lighting in our rooms. The light should be evenly distributed and non-glaring if it is to be used to assist the child's vision. When it becomes distracting the child may attend to the light rather than to the individual directing the learning or the object of the task. If necessary, you will need to add additional lights to overcome darkened areas in the room. When seating the child - he should NEVER face a light source whether it be a lamp or a window. If necessary, cover the windows on eye level and supplement with other light sources.

Adults, as well as children, need to learn how to use their vision for communication - receptive and expressive - with the child. You have to observe and "read" the responses of the child. Also watch your own body language, and gestures to be sure you are communicating what you want the child to understand. Communication is a two-way street, each using many channels of input.

Total Communication and Conceptual Learning

Robert J. Howell

I think it is important to tell you a little bit about myself, my experiences, my feelings, both my joys and sorrows in working with handicapped children.

I am going to say some things today that may shock you a bit, which is O.K., workshops should be a little shocking and help us out of possible ruts in teaching practices that all of us so easily get into.

I am hoping that by knowing a little bit about me and why I feel as I do that you will not be completely shocked out the door, and into your cars before I am finished.

I would like to point out to you my experiences with handicapped children and adults that have had a significant effect on what I am as a person today, and how I feel about the role of educators of handicapped children.

My first significant experience with a handicapped person was at birth. My mother was a severely hard of hearing individual who became close to profoundly deaf and then through a stapendectomy operation regained almost perfect hearing in both ears after 23 years of a severe hearing loss. I have known my mother both as a hearing impaired person and as a hearing person----the effects of deafness even to the adventitiously deaf are tremendous on one's life experiences and attitudes.

My next significant experience with the handicapped was as a teacher aide at a state mental hospital with emotionally disturbed children.

Through this experience I learned that emotional health and adjustment to one's life role is all that really is important, that, and being happy.

The children I knew still haunt me. I wonder if any one of them have been able to meet the demands of what we called the "outside". The main approaches used with the children were behavior modification, psychoanalysis, and heavy drug therapy. No one, except a few of us, really ever got involved with the children. I never saw one child really change in behavior, all changes were temporary. Fortunately some programs are changing behavior today.

My next experience with the handicapped was with both deaf and blind children and adults at a residential school for the deaf and the blind.

I was a houseparent of the honor deaf boys dorm during the evening and teacher of the blind during the day---that was a real schizophrenic experience. Many of my friends were deaf adults, and later when I was married, friends of both my wife's and mine were often deaf or blind.

I learned manual communication skills because I wanted to know my deaf friends better, and soon became aware of the profound affect of deafness on language acquisition and personality when it is congenital.

In the evenings I often spent hours explaining minor idiosyncrasies, details, and (to us matter of fact information) of everyday language experiences to intellectually gifted deaf boys (in a good educational program) who functioned at definitely retarded levels of language concepts and cognition.

I remember substituting for a friend in a deaf class one day and spending one hour in attempting to get my message across to my group. The message was get out a piece of paper and pencil, and answer the questions at the end of the story. Really, to this day, I do not believe those children knew one concept that could have been in that story, or what I wanted from them.

I remember spending 3 years in attempting to teach simple everyday concepts to blind youngsters in attempting them to learn independent travel. I believed and still do, that blind education has wasted years in academics on blind youngsters who still have little knowledge of the skills to meet everyday living needs, as has deaf education.

I would often begin to teach a very bright blind child to independently travel to a candy store and return to school only to find out that the youngster had never seen the inside of a store, who had no idea what an isle was, who had heard but never used or seen a cash register, who had never spent money, it was always spent for him. Who had no idea that there were several types of candy bars not just what mother sent to school.

I later developed a daily living curriculum that I used to teach blind children to travel; it simply was that we never learned to get anywhere until we knew why it was important to get there; what was to be found there; and why; and how to use what we found when we got there. In other words we did not learn to get to a bank unless we knew what a savings account was.

My next experience and the one that has had the most significant affect on me as a person was teaching my four deaf-blind and M.H. deaf children last year. From them I have learned patience. These children have not only the problems of the deaf, not only the problems of the blind and visually impaired (and by the way the vision problems of our children are greatly underrated), but they also have the multiplicative problem of 2 or more handicaps working together to prevent learning.

The point I am attempting to make is that handicapped children are often cheated by being presented methods, procedures, and curriculum that are as meaningful and as important for future life needs as the gaping end of the Embarcadero Freeway.

Sadly enough--I believe that we as educators, even though terribly dedicated, often do not see the trees for the forest.

I have often asked the question--What good is algebra to a child who still cannot tie his own shoes--as many blind I have known.

I have also often asked what good was the ritual of daily hours of readiness and prespeech and auditory training techniques on the deaf child who still does not know what his own name is and that other things in the environment have names too!

If you think I am knocking oralism you are wrong, any methodology can make that mistake, after all why are we doing all these things if not for language. Speech training and auditory training should never be attempted without language.

I am now in the position of being a program specialist to some of the finest and best teachers and aides I have known--not only as a co-worker but as friends.

I have close contact with 46 multi-handicapped and deaf-blind children their teachers, and parents every day. To me there is only one answer to sound conceptual learning in children--that answer is good, valuable, and consistent teaching practices both at school and at home every day.

What I was speaking of earlier, and what I want to reemphasize is where do we want to go, up the ramp of the Embarcadero Freeway, or across the Golden Gate Bridge.

The method I would like to see applied is some form of unit planning for every classroom of M.H. children in California--every teacher knowing on the first day of school in September what he or she will be doing all year.

THE UNIT OF DAILY LIVING

THE COMMUNITY

THE HOME

THE FAMILY

OTHERS

SELF

THE TEACHER'S HAND



APPLENESS
-----COLORS

RED
YELLOW
GREEN
BROWN
COMBINATION

SIZE

SIZE OF LARGE FIST
SIZE OF SMALL BALL

SHAPE

ROUND-LIKE (WITH OR WITHOUT STEM)
CAN BE SMOOTH OR BUMPY

HOW OBTAINED

CAN BE BOUGHT IN A SUPERMARKET
CAN BE BOUGHT AT A FRUIT STAND
CAN BE PICKED OFF A TREE (OR OFF GROUND)

CAN BE EATEN

RAW CUT IN HALF, ETC.
PEELED, UNPEELED

FORMS OF COOKED STATE

APPLE SAUCE
APPLE BUTTER
APPLE JELLY
CANDIED APPLE
APPLE PIE
MOCK APPLE PIE
APPLE JUICE
BAKED APPLE
FRIED APPLES

TASTE

SWEET
SOUR
SWEET-SOUR
SPICES

WHAT CAN WE DO TO APPLES

DRY THEM
COOK THEM; BAKE, FRY, BOIL
BOB FOR THEM
CUT THEM
CORE THEM
MAKE FACES FOR DOLLS (APPLE PEOPLE)

GROWING APPLES

APPLE TREE VS. OTHER TREES
PLANTING APPLE SEEDS (JOHNNY APPLESEED)

Think of the children in your classes--what did they want to say today that they could not. Whatever it was, it is gone forever and shall never be available again.

I would now like to read to you some excerpts from something I felt compelled to write last year.

TOTAL COMMUNICATION - WHY?

I would like to share with you the ever growing philosophy which is an integral part of our classroom. We call this philosophy "Total Communication". It has been developing over the past academic year.

This philosophy grew out of the overall philosophy of our educational program here at the Multi-Handicapped School. This school philosophy states that we as parents, staff, and volunteers will make an all out effort to be open and honest in our relationships with each other, and especially with the children we serve.

Mrs. Ultsch (Instructional Aide), Mr. Courie (Deaf Consultant), and myself had many meetings in the early part of this academic year. It was apparent to us that the four children in our classroom were deficient in two specific areas:

- (1) Language development - The children showed little response to our attempts to communicate with them. No child had an expressive system of language which enabled us to know his needs, desires, feelings or thoughts.
- (2) Behavior - All the children possessed some form of behavior, which was either withdrawal and avoidance of others, or noncooperative. These included lack of eye contact, tantrums, running away, food throwing, to name a few.

The parents of our children visit our program regularly and confirmed that they also found these behaviors to be the most pressing problems they faced with their children.

It was decided that as a team of parents, aides, and teacher we would make an all out effort to communicate with these children, and encourage the children to communicate with us. Hence, "Total Communication" became our philosophy. We decided that all forms of communication must be presented to our children with the earnest feeling that we like them and want to develop a sincere relationship with them. Methods utilized include: Amplification, oral speech, tadoma, manual signs, fingerspelling, gesturing, pantomime, drawings, pictures, photographs, videotape, movies, slides, labeling, writing, and if necessary, standing on our heads.

The results of the team approach of parents, aides, teacher and children are seen as the following:

- (1) All children have a good deal of receptive language which they understand when presented to them by a peer or adult.
- (2) All children have some degree of expressive language varying from a few words to "chit chat" and sentences.
- (3) All our children have shown great growth in social and emotional behavior. We see very little of the behaviors which were evidenced in the "pre-Total Communication" era of our group. We have taken several field trips with our students this year, and have had little difficulty since our children are following the rules of behavior which we have established with them.

In addition, we are observing that two of our students are attempting oral speech. One student has a repertoire of several words, including "Ralph" and "Pumpkin".

Since we are dedicated to openness and honesty through "Total Communication" we do not feel that we have THE ANSWER to the problems of language development with multihandicapped children. Rather, our philosophy is openended and allows for suggestions, criticism, comments, and standing on heads.

Language - What is it?

Susannah J. Kirchner

Language has as many definitions as there are "-ologists" who work defining and analyzing it. It can be defined through the eyes of a linguist, a psychologist, a pathologist, a therapist, a neurologist, an otorhino-laryngologist and a host more I can't even pronounce.

While we as educators don't have an "-ologist" at the end of our title, in order to work effectively and efficiently we must have the findings of the "-ologists" in our heads, hands and hearts. They form the foundation on which we build our knowledge of language acquisition. The basic assumption of all these "-ologists" is the possession of hearing.

But our client, the deaf-blind or M. H. child, starts out without that major source of input - functional hearing. Therefore many of the definitions of the "-ologists" are meaningless for us. We must have a broader, simpler definition of language that fills our needs. Let us just say it is a "mutually understood system of communication."

As the normal child is achieving this system called "language" he is also going through a period of physical maturation and growth milestones. He proceeds from the motoric to the expressive level of operation. At first a stimulus was provided and the child was guided in his language responses. Later he uses that language to interpret, evaluate and integrate his own experiences ("thinking"). And lastly he uses language to communicate experiences and exchange information. Succinctly put, it's world input - child intake - child output.

So? What's it all about? With the normal child, language is about the things he sees, hears, feels, and does. He is motivated to do because of what he hears and sees, which in turn re-motivates him creating a snow-balling effect.

Well and good, but here we are with youngsters who aren't motivated because they don't have functional hearing and sight (and possibly other reasons as well!) We have seemingly met a dead end at the beginning of the road. But it is here that teachers, parents, etc., must set about to remove the road blocks and motivate the child to explore the world about him. We must help him to step into a cognitive world - one of thinking and concept formation. This world comes about as the result of

a person's construction of reality, first through sensory-motor experiences and later through mental pictures formed from these experiences. There sensory-motor experiences are basic to language building but indeed are not done in a vacuum. Language must surround and support them. Today, however, our task is not to develop sensory-motor activities but rather cognitive activities. To take that step into the cognitive "thinking" world the child must be in direct living contact with his environment - he must do or act in his own learning. Through this exposure he will develop a symbol system. Be these symbols spoken, graphic or signed, they are the product of thinking and provide a systematic representation of life's experiences and serve as a universal means of communication.

Let's look at a few of the last points mentioned with the teacher in mind. 1.) Symbol Systems Which one do you use? Reading, writing, speaking, lip reading, amplified residual hearing, signing, finger-spelling, braille? Whatever system you use make sure it has no holes or gaps for the receiver. As an example, lip reading alone, would be a poor choice for a child with limited vision, when children with normal vision can only see 35% of our language on the lips. Likewise, a purely graphic system would prove too difficult for a child with motor involvement. You can do the arithmetic on the rest of the systems and you'll find not one is complete unto itself. We're left with only one possible solution - use them all!

2.) Living contact with his environment - here's your chance to shine - to bring him into his world and be a part of it. Help him to do - to understand - to explore the cognitive areas of spacial and temporal relations, seriation, classification. These areas are the basis for providing language input. But certainly, one just doesn't decide - "on Tuesday I'll teach seriation to my class." Now, it must be part of central theme or concept, that is meaningful to the child. We call this idea "teaching a unit." You may think this is "old hat" but we've only to look at all subject matter taught from K to University level to see that an integrated thought or unit is its base. Better than "ball", "fish", "top", and "shoe" which are unrelated, uninteresting and unmotivating!

3.) Through exposure - For us this implies a great more than mere mention in passing. It means constant repetition in a million or more meaningful ways in each step of that ladder of cognition. It means doing with him - encouraging and praising each small step of the way.

Let's look one more time at this symbol system or language. This time at what it is not for us. It is not knowledge of syntax, structure or grammar. That knowledge is "linguistic competence" which is merely a secondary aspect of language. It is quite possible to have intelligent language usage and have no or poor linguistic competence. The toddler who says to Mama with arms out-stretched "Up" has intelligent language usage but poor linguistic competence. In time, the latter will come.

The crux of that paragraph is therefore - first things first - concept comes before syntax. We must guide our handicapped child through the same developmental sequences as normal children. Granted it will be slower, and taxing on all concerned but this natural progression will be far less frustrating for teacher and child in the long run.

Normal developmental patterns are too lengthy for discussion here. But if you are not familiar with them, they are available in a number of sources. They should take top priority on your list of "professional improvements."

Where do you start this input process? It should go on all the time but for specifics, take something that interests the child. If he has no interest, choose one appropriate to his level and build.

I chose a book and I'll build on it or "milk" it to show you what I mean. By no means would any one teacher do all these things at one time. I do this merely to show the possibilities in a few printed pages.

The Book - Sweet Smells of Christmas (by Patricia Searry)

The experiences possible: (going through book page by page)

- 1.) Baking apple pie
peeling, cutting, rolling, mixing, baking, eating, smelling
- 2.) Cutting down a Christmas tree
running through Christmas tree farm
- 3.) Trimming the tree
making ornaments
- 4.) Hanging the candy canes
smelling, eating some too
- 5.) Making gingerbread men
mixing, rolling, cutting, putting on the buttons, eyes, etc.,
eating him up
- 6.) Making Hot chocolate
mixing, cooking, melting marshmallows, drinking, maybe dunking
- 7.) Visiting Santa - or having Santa visit you
He's big - fat - soft - round
- 8.) Eating an orange
rolling, cutting, squeezing, drinking, eating

- 9.) The presents
 wrapping boxes, unwrapping boxes, the gifts inside
 Make the gifts the items they need to know - their toys,
 clothes, articles they use, comb, brush, etc.
 Great opportunity for guessing, shaking, untying and tying.

Some items to use in this presentation:

- 0.) Real items (not bears, of course)
- 1.) Felt board materials lifted from book (pelon tracings with crayon)
 - 2.) Felt puppets - role play and theater play
 - 3.) Stick figures - role play
 - 4.) Paper bag puppets
 - 5.) Bottles for sniffing
 - 6.) 3 bears (stuffed) - counting
 - 7.) Book
 - 8.) Art activities related
 - collage - "decorating" a paper tree
 - Painting - paint paper to make it wrapping paper, wrap the gifts
 - Play dough - make, color it, scent with orange, make oranges or whatever, or use Christmas cutters
 - Printing - use fruits, orange and apples in story to print with - using tempera

Lastly, I'd be sure to photograph all these activities so in the end the child would have his own book.

Where do we go from here? Have you considered "The Three Bears"? A great chance for seriation, size, family concepts, eat - break - sleep and so on. Reinforce the concept "3."

And then, from there, try the gingerbread man. He was in "Sweet Smells" as a lesser character and in this book he's the lead. Make him again - he cooks, runs, meets up with some interesting friends - among them a pig.

So why not make the next step into the world of the 3 pigs! And so on it goes.

Now a word on some other materials unrelated (at this moment that is!) to this unit.

About home made materials in general. Think them through well, so each one may serve a variety of purposes. It cuts down on storage space.

Items on oaktag should be of standard sizes. Start with good large base size and cut it down by halves, giving you about 5 or 6 possible sizes. This will make neater and more economical storing. By all means use good clear pictures or drawings. Laminate both sides. This prevents curling and peeling.

Cigar boxes (which are solid gold by the way) are great for storing small items. Flat mint boxes are wonderful for felt board material.

In the long run, it is cheaper to fly all of you to my house than to bring it to you. Just a sampling: (things I demonstrate)

1. Disneyland Games (friends, animals, numbers, colors, things that go)
2. Geo-Boards
3. Tupperware Ball - using play dough or cookie cutters with the shapes
4. Marble Box
5. Sequencing Box
6. Busy Book
7. Outline Game
8. Wonder Envelope with inserts
9. Triangle Parquetry
10. JTC Fast Slow Games and Cars (auditory training & speech)
11. What Do Animals Say (auditory training & speech)
12. Overhead Frame Vocabulary cards
13. Our Trip Book + What Do I See? (home made books)
14. "Match" Board and envelopes
15. String Across
16. See-Quees and Sequence #16
17. Box with Color Cubes

18. (2) Three Bears Books and seriation cards
19. 15 cards and Sequence #88
20. Next Time (a Wordless Reader by Whitman)
21. Linoleum Matching Shapes (home made from samples)
22. Make a Face (book)

Basic Steps in Building Communication

Mrs. Sandra Meyer

"Your child does have a vision and hearing problem. I'm sorry I cannot tell you how to help your child or teach him." How often parents have heard this same statement from various professionals and non-professionals! You, as parents, have turned anywhere that might offer you some suggestions or assistance, but most of the time have been frustrated in your attempts.

How does your child with very special needs learn to be independent - feed himself, dress himself, etc.? A term that is often used in the field of education for the deaf-blind child is co-action. Co-action is placing your hands over your child's, your body over his body, while you actually move through an activity. You become an extension of your child's arms, hands, and body and he of yours. It is through you that he will learn.

When do you use co-action? I would say all the time, until your child is able to do the specific activity by himself. For example, use co-action when helping your child get dressed, use a spoon, learn signs, experience new things. Gradually your child will try to do things by himself. Look for signs of independence, and gradually withdraw your physical support. However, when he does need help, don't hesitate to offer it. Remember, always, to praise your child for even the smallest attempts. Your love and support is important to him.

Communication between you and your child is a prime concern. Where do you both begin? Communication between people conveys feelings and ideas by using several forms of language. The first form of language between you and your child is body language. There is an input of emotions through handling him - hugs, pats, and the warmth of being close. When you hold him close and sing or speak in soothing tones your son or daughter receives a feeling of protectiveness and love. When you are tense or upset, these feelings are also transmitted through the vibrations and tonal quality of your voice, and the manner in which you hold or handle him.

During this period of development in communication, receptive language is taking place. You are "feeding in," but at this time, your child is not yet returning or expressing any language through verbal language, sign language, or printed words. All children must first be exposed to receptive language for a time before they

will start transmitting their needs and thoughts through a form of expressive language. Each child is an individual and, therefore, this time lapse between receptive and expressive language will vary.

As your child becomes aware of your symbols of communication, he will start to imitate them. He will parrot your words or signs immediately after you express them. It is through imitation that much of your child's learning will take place. After repeatedly observing your language in direct association with what it represents - an object, a situation, or an action - and experiencing your words or motions many, many times, he will some day spontaneously ask a question or express his needs through his means of communication. First and foremost to enable your child to learn through observation, experience, and imitation, so he can be aware that you are communicating with him, you must obtain his attention. Get down to your child's level whether you have to do a deep knee bend, sit in a low chair or lay on the floor. Make sure the light is on your face to help him focus on you.

A child's ability to observe and imitate starts first with large muscle movement, like crawling or waving his arms. Gradually his coordination becomes more refined and small muscle movement develops. His ability to pick up small toys, imitate a sign, or handle a button will be noticed. He is growing from a dependent baby to a child gaining new independence each day. And it is mostly through your patience and love that these changes will take place. You have a unique, difficult, but rewarding job.

This role of parent-teacher has been thrust upon you with little or no previous training. Dr. William A. Blea, who, you know, is Director of the Southwestern Regional Deaf-Blind Center, realized a threefold need for a correspondence course for parents of deaf-blind children - early intervention in the child's training, parent education, and a consistent home program whether or not the child is enrolled in a school program. The child who is participating in a local school program still spends the majority of the time in the home. A correspondence course to be used at home will help the child gain that much more from his school program. There will be structured, meaningful learning being offered all the time. John Tracy Clinic was selected as the place for development of this new Correspondence Learning Program for Parents of Preschool Deaf-Blind Children, since it had been involved for so many years in parent education and in correspondence education.

The new course is unique in correspondence education - it caters to the individual needs of each child. The program is divided into two major parts. The first division consists of twelve parent information and attitude sections and twelve lessons on communication. The second major half contains learning steps in seven different areas - gross motor, fine motor, eating skills, sleeping habits, dressing skill, toilet training, and personal hygiene habits. Each child develops at a different speed in each area. Therefore, in order to prescribe an individual program for that family, a check list is filled out providing

us with a behavior profile. The parents are also asked if there is an area of special concern on which they choose to focus. After examining the returned check list, we find, for example, a particular child is on level one in sleeping habits, dressing skills, personal hygiene habits, and toilet training; level two of fine motor skills and level three of gross motor and eating. This family may also state that they have a special concern with eating habits at this time. Thus, the family will receive Lesson One of parent information and communication, Learning Step Three of Gross Motor, Learning Step Two of Fine Motor, and Learning Step Three of Eating. Parents will receive Learning Steps in other areas of development as they feel ready. Each time a parent receives a new lesson, a personal letter is always enclosed. This provides our staff at John Tracy Clinic a means of building a personal relationship with each family. Your job as parents, if enrolled, is to feel free to express your feelings - frustration, anger, love and happiness; and to keep us informed of how and what your child accomplishes each day. Our job is to lend an ear, to offer support and encouragement, to offer suggestions to fit your child's needs. We are here to help you and your child with your special needs and his.

In the beginning, your child will receive your help through love and co-action. Ultimately he will have learned to communicate in his own way and to do particular actions by himself. At this point, your job is to be a coach - gradually withdrawing your physical support as your child gains each step towards independence. He will continue to need your love and emotional support.

Play as a Learning Experience

Bea Gold

I would like to tell you a little about myself before we start to talk about the topic of play with deaf-blind youngsters.

Within the last few months, I have come to look on my role in working with teachers rather differently. I had two experiences -- one last summer and one just recently that made me stop and evaluate what I saw as my profession. I have been involved in early education for the past 15 years and specifically in education of the handicapped for the past 10. Until these two related experiences, I thought of myself as an Early Childhood Educator working in the field of Special Education.

However, last summer I provided an in-service program for 60 teachers of young deaf, mentally retarded, and orthopedically handicapped children, using as consultants the International Center for Educational Development. This group presented two six-day workshops for teachers on open education based on the British Infant Schools.

There were many reactions to the in-service program from excellent to absolutely terrible. I realized that the greatest difficulty encountered by teachers was in mentally adapting what was being presented for non-handicapped children to the specific learning environment of the individual teacher. If she was working with only six deaf children and they did not have some needed skills and could not hear directions, could she still develop a program based on the basic concepts of the presentation?

At the second session of the workshop, I remained as consultant and teachers with similar problems grouped together to discuss some methods of opening up their programs. This helped somewhat, but the teachers requested that any future planning be done especially for them so that they could really explore ways of providing exciting programs for their youngsters.

The second occurrence, which made me stop and think about who I was, was the presentation of a beautiful in-service program by Molly McVicar of Pacific Oaks College. She is a very capable and dynamic Early Childhood Educator, and her presentation was on integrating creative thinking into the basic curriculum of an education program. Her audience was the staff of the Sophia T. Salvin School which is made up of teachers of trainable mentally retarded, orthopedically handicapped, multiply handicapped, and

teachers of an integrated program of handicapped and non-handicapped children.

As her presentation progressed, I found myself becoming really enraptured. She was talking about asking children what the moon looked like to them, or made them think of. She asked the audience for response, and all of us were really letting our imagination go with things like "a snow ball, a silver sliver, a pumpkin, a boat sailing in the sky." Suddenly I heard a small snicker behind me and someone said with sarcasm, "I'll try that with my class tomorrow." I turned and realized that it was a teacher of young trainable mentally retarded children and, truly, if she tried that experience tomorrow, nothing would happen. Should we throw the concept of creativity in thinking out for mentally retarded or do we have to think about ways of adapting the experience to the level of the child?

I realized that the problem with this presentation and the one the past summer was that the leader was unable to really get "into the heads of the children" and although in each case the people were excellent in-service leaders, they had not had experiences with children who were physically, sensorially, or mentally limited and were unable to help teachers make the translation from the concept of "good for all children" to "how specifically for mine."

These two separate incidents have made me look at my professional role differently. I now see myself as a Special Educator specializing in Early Childhood Education. My specific purpose is to help teachers find ways of providing what we know, from child development studies, is relevant to all children. These include the non-handicapped middle-class child, as well as those who are in one way or other deprived of the ability to maximize learning opportunities.

I don't believe I can "get into the heads" of all of your youngsters, but I hope together we can explore some ways of providing experiences for them which at times appear to be impossible.

Most teachers of exceptional children have been trained to think about the specific needs for skills development for their children. Teachers for the deaf-blind have more areas of need to try to help the child compensate for than any other group.

In most programs, our children's days become filled with structured activities, developed because of the assessed needs as seen by educational specialists. The teacher, speech therapist, occupational and physical therapists, and medical personnel often work together to diagnose the problem and prescribe a program for the child, or the teacher may be left to develop her own program with only occasional assistance.

If we believe that play is a base for learning for children, we need to build our programs to include time set aside for the development of child-directed activities.

Aaron Auerback has recently critiqued Arthur Koestler's theory of creativity and has directed teachers of young children regardless of their developmental handicaps to think in terms of relaxing structure. He uses the term, "bisociative act," to describe creativity ability of any child. He describes the mind as a pyramid, the base being,

self-regulatory physiological process,
then habits and routines,
abilities and skills,
learning and associative thinking,
and at the top, free play

The bisociative act is the bringing together of the various levels.

He describes the creative act as any sudden, new, unique, and original happening in any of the areas, and that even though the structure of a given program will differ for different children, the principle of relaxing the structure for the purpose of maximizing the creative act for a particular child will hold steady.

The article has appeared in both The International Journal of Early Childhood in a very scatteringly form, as well as in Young Children, The Journal of the Association for the Education of Young Children. I have reproduced the article from Young Children and have it available for you.

Sincere educators frequently meet with conflict in their attempts to provide a structured skills development program, as well as finding ways of providing unstructured play experiences.

Trying to develop programs that maximize both these components of a child's learning experiences has proven to be a great challenge.

Three years ago, we developed an early childhood program to be used as a model. The concept being to integrate a skills development period, which can be organized on a diagnostic/prescriptive approach, and also include a portion of each child's day when the structure is relaxed enough to provide for independent action on the part of the child. The skills development portion of the day is called the Formal Time, while the child selected portion we call the Option Period.

This program was developed as a working demonstration model to provide in-service for teachers who also were troubled about offering an incomplete program for young children. The model was established at the Salvin School in Los Angeles for orthopedically handicapped children. Consultant help was available to establish similar programs in special education early childhood programs.

We now have programs using this concept in eight of our Special Schools and approximately 60 teachers are working with this model.

We call the approach DEAL or the Dual Educational Approach to

Learning. As time has gone on and we have replicated this program for a great variety of children, I find I learn more and more about structure and freedom for children.

Teacher's interaction during the option time needs to be different with each individual child. We are now integrating handicapped and non-handicapped children in our program and find that teachers look at their handicapped children in a much more positive light. They simply did not know what the children are capable of.

In many programs we find that children need to learn how to play, and what materials are for, and how to use them. Often teachers find that they need to play the role of another child in order to help the child learn to play.

In programs for the blind, we need to consider that the totally blind child needs to be introduced to each play area through touch, and the environment needs to remain constant so that after mapping an area, they can find then what they wish to play with.

Some children need help to focus attention on a particular area; another is learning to control his body; another is testing relationships with children; while still others are practicing skills that they have not yet mastered. Some children are capable of structuring their option time so that it is full of new and exciting experiences, while others need to remain near a familiar adult or with a familiar activity.

Using Piaget's theory of play, we see most of the children we deal with on a sensorimotor level, and as such, we are challenged to provide an environment in which children can interact with materials and people in a way that permits exploration, practice, and the ability to relive experiences through play.

The adult's role in this kind of environment changes from that of authority figure to one of resource person who interacts with both materials and children in ways to encourage exploration, looking for that bisociative act that is new and creative learning for this child. Did he go to the toilet by himself? Was he able to predict that a whole block structure would fall if he added one more block?

Three component need to be coordinated in order to develop a Dual Educational Approach. The three are: the use of manpower, designing the environment, and structuring time.

In order to develop an option program, we have relied heavily on cooperative teaching. In a situation where we are working with the child who often needs help in accomplishing what he sets out to do, we find that by grouping teachers together, we can provide adults at many centers that children can learn to select from. No matter where a child wanders in the fully staffed option program, he will come upon an adult ready to work with him, if he chooses. Or the adult if able to sit back and observe for the time to interact and look for evidence of needs and growths.

A very interesting concept of interaction between children and materials has recently come to me. A visiting British Infant School representative was offering a workshop and she related the child's interaction with materials as a conversation between two adults. The material talking to the child -- as in block building, where the addition of another block makes the structure sway. The child talking to the materials in manipulating and observing what happens. Just as any adult entering a conversation between two adults would be careful not to interrupt by waiting to see if the conversation is private, or seeing if you have nothing new to add, or speaking up if, in fact, you could add something of value without interrupting the conversation.

Teachers and aides in this program assign themselves to each of a variety of areas and set up and maintain that area for the option period. One teacher acts as the guidance person and is responsible for maintaining the stability of the program. I like to think of that person as the stirrer of the soup pot. She adds salt, skims off the top, and keeps the soup at a low simmer.

In some programs, teachers reassign themselves once a month; in others, it's a weekly interval.

The design of the environment is dependent upon the site. In some programs, we have option programs taking place all outdoors; in others, all indoors. While in some fortunate programs, the activities take place both indoors and out. In each of the sites, basic learning centers are developed. These include dramatic play, a manipulative materials center, block building, the activity of the day table, which may include cooking, art activities, woodwork, and a large motor area. Water play is often added, as are dance and music experiences.

The materials and activities are designed to be open-ended, needing a minimal amount of direction so that children of differing abilities may experiment and work at an individual level.

The time structure for each program usually keeps the option time at between 40 minutes and an hour, so that neither teachers nor children need to feel rushed to finish. Clean-up is the responsibility of all and is set aside as a time segment.

The goals for children during this period are for independence, creativity, communication, and cognitive growth. Skills development are provided if children show a desire to practice what they have already begun to learn, but the option period is not considered a time to formally introduce skills. The option period provides an excellent opportunity for teachers to observe and assess children's needs for the formal skills development period.

Program Planning for the Multi-Handicapped Child

Caro C. Hatcher Ed.D.

The organization of sensory experiences that enables a child to perceive structure, order, and meaningfulness and relatedness of events in space-time, is the most profound need in the growth and development of any child and the multi-handicapped child is no exception. In fact such a need is greatly magnified in the life of the handicapped child and warrants considerable insight and understanding on the part of parents, teachers, therapists, and others who are involved in the habilitation of children with one or many handicaps. The organization of sensory experience in the early learning period of the child's development is the keynote to his functioning. The ingredients of this organization are intricate, multi-dimensional, should be scientifically propelled, and are basically related.

Multi-handicapped children are both sensory impaired and sensory deprived and such deficits tend to enhance "isolated" and "fragmentary" learning with little or no relatedness to space-time orientation or to meaningful functioning. Raw sensory data are insufficient to produce or to explain the coherent picture of the world in which the handicapped child finds himself. Further complications arise as we examine our modern automated society into which the child is born. Automation provides a "cart before the horse" approach to learning in that abstractions precede the concrete. This problem exists throughout the whole repertoire of sensory input. Language development is specifically affected in the "cart before the horse" approach. Language is any symbolic communication which is coded into symbols that represent objects, persons and actions with meaning. Too often verbal language, relating to verbal symbols only, is imposed upon the child, before he has experienced direct and meaningful representation or what might be defined as inner language.

From this cursory glance at some of the problems encountered by the multi-handicapped it behooves us to take a look at the early structuring of the child's environment; herein lies his most dynamic needs. To analyze these needs a careful look at the significant periods of development in the growth of normal children is necessary. The first period, from birth to two years, has been designated as the sensorimotor stage. This period can be subdivided into the age levels of 0-3 months, the reflex period; 3-9 months, the eye-hand-body coordi-

nation period; 9-15 months, the period of mobility, and 15-24 months, the period when movement is perfected. As we observe all children's growth and more specifically the development of the multi-handicapped it is significant that help be given the child in his transition from early reflex movements to purposeful initiated movement. The child's movement activities act as both messengers and handmaidens to his nervous system and without purposeful body involvement his functioning is lopsided and void of complete meaning. Movement delivers information from the outside world to the cortical brain centers where evaluation, approximation, classification and preciseness of meaning transpires and the implementation of a course of action is determined from the information thus processed. Herein lies the greatest and most significant need of handicapped children. All interferences that impede the movement experiences of handicapped children should be controlled. These range from environmental reflections of tensions and physiological influences to that of deprivation. The child needs assistance in acquiring a gestalten concept at this level and we are obligated to engage in a more analytic study of each child's needs as we strive to improve his surroundings in an effort to offset negative feedback in his environment.

At this point I would like to present slides of the movement activities I use throughout this sensorimotor period. (They include what hands can do, hand and body coordination activities, movement through all kinds of sensory media, movement and sound, and many other activities that help to wake up the sensorium of the child.)

As such purposeful movement evolves, hand-body and eye coordination gets underway. Added sensory assimilation of whatever visual function prevails, auditory awareness, tactile, and other stimuli aids in evoking the motor conditioning process into a larger pattern of heightened exploratory activation which in turn, accelerates the growth and development process. On the other hand, if the environmental influences have not been appropriate to the needs of the child, immobilization of this process can occur. These conditioning processes involve increasing differentiation as stimuli become more usable by the motor apparatus of the child. Thus the early developmental patterns of the child's growth become a prerequisite for the mastery that is to follow, an essential need of the multi-handicapped child. Too often this sequential order is broken and only fragmentary information is received.

The third period involves the total body. The child rolls outward into space, creeps or crawls into it or uses a scooting technique or any other modality for getting from the "here" world to the "there" part of it. The multi-handicapped child may be deprived of this spontaneity in mobility and his explorations of the outer world are void. Accordingly the voidness of that outer world becomes a threat to him and he develops an attitude of fear. All through life our emotional states are a reflection of our attitudes toward space; the world can be a sunny open place or it can be "closed in." Our feelings vary in accordance with the tenor of our experiences in mobility or the restrictions thereof. An individual arrives at an inner space reaction to

outer space which is a measure of how he perceives an outer space reaction to his own inner space concepts which is a measure of how he feels. The assimilation of the two becomes his total body-mind awareness. The multi-handicapped child's needs in this area are significant; we must scientifically propel his explorations by appropriate simulation of the movement necessary for him to experience space objectively. Much more concrete and realistic experiences are needed at this level than are commonly emphasized.

As a child enters the fourth and last stage of the sensorimotor period he is subjected to an interaction with his peers which, in turn, is a further benefit to his learning. Many multi-handicapped children, however, do not learn to interact with other children thus creating further deficits in their information input.

Interrelated with these stages of motor development have been the precursors of speech per se which include sound input, visual awareness of lip movement, perceptual processing, and simple concept formations. At this stage expressive and motor encoding is the center of the language process; the thought processes are encoded into a symbolic form suitable for the child's communication. In this particular category all handicapped children need to be subjected to a "Helen Keller" approach to symbolic representation. Sensory integration must be complete; a child may have a wealth of dissimulated sensory input that may glow as fragments of the learning process but are inconsequential to language if not integrated and related. Language unfolds in a constant interchange of action that involves the manipulation of objects and the internalization of thought.

(More slides are presented here to illustrate early language development. Also, remediation techniques necessary for habilitation of handicapped children with language deficits are offered. Demonstrations on how to make use of residual visual and auditory input including dark room techniques are included.)

The maintenance of an attention span and attention awareness at the desired threshold for meaningful absorption of sensory stimuli is essential in working with children. If we make the experience enticing enough for the child and reasonably commensurate with the child's assets for functioning we are seldom disappointed in the "attention" to the stimulus at hand. The one exception to this rule might be the child with a low physical stamina for endurance of certain physical fetes but herein is the need to employ careful insight.

The remaining needs of the multi-handicapped child can be identified with the needs of the various individuals who work or come in contact with the child. A thorough parent education for all parents of the handicapped is essential to their children's welfare, growth, and development.

A more basic knowledge of multi-handicapped conditions and the nature of the implications thereof are needed by the general pediatrician

in order to assure proper referrals for early adequate treatment and care.

Teachers and other personnel working with the multi-handicapped need to be knowledgeable about how learning takes place, about growth and development procedures, and child behavior. They need to have an awareness of the importance of structure in programs for the multi-handicapped, the significance of "sequencing" children's exposures and explorations in learning, the dynamics of incentives and last, but not least, an understanding of human values and the self-worth of the individual. Thank you.

Psychosocial Problems of the Handicapped Child and His Family

Justin D. Call, M.D.

DEFINITION

A handicapped person can be defined as an individual who does not gain maximum satisfaction or opportunities for development and survival in life. The culture in which we live both influences the kinds of satisfactions we can gain and the degree to which our potentialities can develop, and thus adds an important dimension to the definition. A biological dimension is suggested by the fact that each species is both gifted and handicapped with regard to other species. Since death comes to all individuals, it can be stated that in the long view each of us is totally handicapped. The individual, the family, the culture, the species and genus each survive for increasingly longer periods in the order named. These facts should give us a better perspective on the problems to be presented and should bring us to a closer state of empathy with the more severely handicapped persons among us.

CLASSIFICATION

Viewed in this broad sense there are three general classes of handicaps:

1. Normal constitutional variants: (genetic variations in development within generally accepted limits of normality). These include general intelligence (High intelligence may be a handicap in a society which stresses standardization), body height ("too" large or "too" small), general appearance (hair, skin, eye color, muscle mass, fat distribution), functional differences (differences in sensory perception, neuromuscular coordination, special creative talents or lack of same).
2. Abnormal constitutional variants: deficiency of some body part or parts, such as blindness, deafness, cleft palate, malformed or absent extremities, mental retardation, mongolism, congenital heart disease, cerebral palsy, hemophilia, myopia, congenital cataracts, tracheoesophageal fistula with esophageal atresia, defects at a molecular level as with sickle cell anemia, thalassemia, phenylketonuria, agammaglobulinemia, etc.
3. Acquired abnormality due to illness: such as asthma, poliomyelitis, arthritis, renal disease, burns and trauma, all forms of chronic illness and mental disorder.

The degree of handicap itself cannot be related in a linear fashion to the degree of constitutional variation, congenital deficiency or acquired abnormality but pertains to functional limitations or, in a biological sense, to the limited capacity of the individual to adapt to and creatively use the environment. The factors which determine the degree of handicap in each individual are as follows:

1. The age of the child and time at which the handicap occurs in the individual's development.
2. The degree to which the actual handicap is accurately perceived, understood and accepted as part of the self.
3. The attitude of society toward the individual with a handicap, i.e., how much variation is tolerated? What are the cherished values of the society? (i.e., manual vs. mental skill, speech vs. performance, being dependent on the larger family unit or group vs. complete independence from family and group).
4. Physical aspects of the handicap itself, i.e., the real limitations.
5. The success of rehabilitative techniques directed toward correction of or compensation for the actual handicap. This is very much dependent upon the above factors.

Psychological Implications of the Handicap

Being handicapped implies being different from others. Such differences in appearance or function may have repercussions upon the child himself, the child's mother, father and siblings, as well as his own peers and social group.

The Child's Problems: The very young infant and child has no awareness that he is different from other people though he may have a severe handicap. As long as his basic needs are met and as long as there is reasonable opportunity for growth and for the appropriate expression of underlying instinctual impulses, he remains at relative equilibrium within himself and with respect to the outside world. Such equilibrium is rare in the "normal child" and less likely in the handicapped child.

The external struggle of the child: The problems the child faces in dealing with the outer world are usually more easily recognized than those with which he struggles as a private matter. The outer world problems include such difficulties as: communicating with others, establishing friendships and feelings of belonging in a group, achieving recognition, becoming educated insofar as possible, finding sources of play, recreation and work compatible with limitations imposed by the handicap, and finding suitable "love objects" other than parents and immediate family.

It is relatively easy for the parents, the professional person and society at large to empathize with the handicapped person as he struggles for solution to these outer problems. It is more difficult for parents, professional people,

and society to conceptualize and recognize internal struggles. It is even more difficult to determine the way in which internal struggles influence and interdigitate with external ones. It is important to establish such differentiations because when help is offered to the handicapped person directed specifically to deal with the external struggles, it is often not used effectively by the person. This may lead to disillusionment both to the handicapped person and to the parent, person or agency offering help. This in turn may lead to further estrangement of the handicapped person from the environment rather than greater satisfactions and utilization of opportunities offered by the environment.

Internal struggles: A handicap which imposes prolonged dependency on the individual makes it very difficult for the person to move beyond this period of emotional growth even when all external factors have favored such progress. This struggle lies in the fact that the tendency to cling to the dependent position is in conflict with the tendency to progress in development. Parents often report sudden spurts of both growth and regression in their children as an expression of this internal struggle.

Another internal struggle is brought about because of the thought the child himself may have about the handicapped part or limitation of function of his body. A young child cannot view the handicap in the same cool, rational way the professional person can. He nonetheless has ideas about it and these ideas are often intertwined with the ideas and feelings he has about his body and its general functioning. A boy may, for example, on discovering that he has limitation of muscular strength, mobility or coordination in comparison to other boys and men, feel less capable of fulfilling a masculine role and he may view the handicapped part of the body as the defect responsible for this. Strong feelings may therefore be centered about the handicapped part of the body. In phantasy he may "solve" the problem either by denying the presence of the handicap or by failing to grow up emotionally so that the implication of his defect will not have to be admitted to awareness. Ways the child has of looking at and reacting to the defect will influence to a large extent the success of efforts to correct the defect or improve upon its functioning. The child may, for example, look upon outside efforts to help him as possible further threats to him and become fearful, angry, and uncooperative to such procedures as physiotherapy, nursing care, physical examination, etc. especially if such activities are body-oriented rather than child-oriented or if therapeutic procedures themselves are designed with an artificial pattern in mind which does not make sense to the individual child in his own individual environment.

A child may develop the idea that it is through the handicapped part of his body that all of the important and meaningful communications with the outside world take place. This is not surprising when one realizes that parents, family, doctors and society generally are so often stunned by the defect that this is all they see of the child. The child may learn to see himself through his defect and may model his personality in an image closely resembling it or may use his defective part as the part of the body invested with most of his emotional feeling including sexual feeling. For example, children with Osteogenesis Imperfecta have often been observed to develop very delicate, fragile, careful and well-insulated personalities.

A severely handicapped, normally intelligent adult cerebral palsied man once observed that he would become sexually excited when he thought of and visualized a leg brace. Such thoughts would come to him during masturbation. In actuality he found himself attracted to women who did wear leg braces. He had himself worn a leg brace as a child. One may surmise that he had invested a good deal of feeling in the brace itself, and furthermore that he received a good deal of parental attention through the brace which was equated by him as love. This example shows how the handicap itself may serve as a crystallization point around which sexual and aggressive feelings may gain expression.

The way in which a child learns to perceive his own limitations will determine the degree to which his real handicap will be accurately appraised and integrated into the self without neurotic distortion. Since much of what the child thinks of himself is derived from conscious and unconscious attitudes of his parents toward him and his handicap, parental perception, understanding and "acceptance" are of great importance in determining the child's view of himself. The parents whose perception, appraisal and emotional acceptance of the handicap is neurotically distorted will quite naturally be unable to help the child gain a realistic idea of the limitations imposed upon him by the handicap. There may be denial of handicap by both parents and child so that as growth occurs and as maturity is reached the individual may emerge with the idea that there is no handicap at all, or in other situations the handicap may be used for secondary gain. This will make rehabilitative techniques impossible until such attitudes are corrected. In many families the handicapped child becomes the pivotal group member with all other members, activities, and interests centered upon him. The mother is usually most involved and communicates this hierarchy of values to other family members. As a child grows up in such a family he quite logically assumes that his egocentric position will be maintained. When this position is not supported by society as it was by the family unit, anxiety and frustration occur and the individual may react in several different ways:

He may return to the shelter of the family and continue his dependency upon them despite his capacity for independence. Later, as members of his own family age, die or become infirm, he may again try for existence away from them or find his way to some kind of institutional existence where continued dependency can be maintained.

He may use his "rejection" by society as a form of self-punishment from which secondary gain may be derived, i.e. "I'm sorry for myself...I am entitled to pity and care by others...won't someone please rescue me from this fate."

He may attempt continued domination and control of society as he did the family group. This may be successful as was the case of Richard the Third (for two years) as he reigned in terror and grandiosity and finally met his death after losing his horse in battle. See below.

He may become depressed, suicidal or manipulate whichever persons, agencies, or other social groups he can for continued dependency gratification.

Psychosis may result. In certain instances in which the symbiosis between child and parent is particularly intense and has been lifelong in its development, a breaking of the child's relationship to the parent for whatever cause may result in a serious ego defect in both the child and the parent. Such a break in relationship is similar to that often observed in twins. The tie between child and parent is so intense and functions of child and parent are so interrelated that a break in the relationship leaves an important part of the ego absent in both child and parent resulting in serious malfunctioning of the ego and psychosis. This can be observed in older handicapped persons and their parents who, for one reason or another, must be separated.

He may seek social or psychiatric help for these uncomfortable feelings.

Problems of the Parent

Reality problems: The occurrence of a seriously handicapped child in the family presents many realistic problems, and in the case of cerebral palsy, where the handicap is multiple, these problems become more complex. Parents of such children struggle with a period of uncertainty and anxiety prior to the establishment of the diagnosis. They have considerable interest in the cause of their child's condition, and few know what the cause is. This adds to their anxiety. In a study of parents of cerebral palsied children it was revealed that most of the parents demonstrate to some extent feelings of alienation and isolation from family and society in general. At times, open conflict with society was present. At times the handicapped child becomes the focal point of marital conflict. Most parents grasp frantically for some kind of help for their child. This often takes the form of demanding and often sacrificing for special services for the hoped-for "cure." In the background always was the dread of knowing the outcome, and along with this the problem of institutional care. A positive program of care, however elementary, may furnish a rallying point around which the parents try to work out their problem.

Deeper psychological problems of the parents largely unconscious:

(a) The defect in the child may be regarded as a defect in the parent and in the parent already narcissistically oriented, such a defect may be regarded as a serious blow, a threat which must be defended against by denying the defect or its real nature in the child. This may lead to "doctor shopping" or to a search for a magical cure, or it may lead to an attempt to fix "blame" for the child's condition away from the self and search for vengeance and retribution. Doctors, therapists, and other authorities may often make themselves unwittingly convenient targets by arousing feelings of resentment because of poorly timed or rationed advice or help.

Conscious or unconscious wishes that the child had died at birth or thoughts of killing the child or having him meet a similar fate through other means are not uncommon. These thoughts (death wishes and hostile impulses) present a threat to the parent because it is not acceptable for a parent to have such thoughts or impulses toward his own helpless child,

dependent on him for love, protection and sustenance. In order to protect himself from having these thoughts come to his conscious awareness, these ideas and impulses may be dealt with by converting them to opposites (reaction formation) thus protecting him from acknowledgement of unacceptable impulses. Such protection, sustenance and shelter are overdone "just to make sure". In some instances such death wishes or hostile impulses may become conscious and actively expressed to a greater or lesser extent. The defenses against these feelings are usually more evident in the mother than the father because the mother is usually in more intimate contact with and responsible for the child. Occasionally the child-caring roles of the parents are reversed and there it is the father who is in most intimate contact with the child and most overprotective, sheltering and infantilizing.

(b) Feelings of inadequacy for having produced a handicapped child are almost universal. These may reactivate earlier feelings of inadequacy and may be defended against by overcompensation for these feelings by becoming the only person who can care for the child.

(c) Guilt feelings: These may be derived from underlying rejection of the child or feelings of responsibility for having caused the handicap by some actual occurrence, feeling or phantasy during pregnancy, or through some "sin" in the past.

(d) Mutually inhibiting parent-child symbiosis: One of the commonest questions asked by parents of the severely handicapped child is, "How can I help him become independent from me?" In a study of parents of children with cerebral palsy the parents were concerned in three out of four cases with this question: "Does the handicapped child need more love and attention than the child who is not handicapped?" Further discussion of this question often leads parents to a recognition of the intense nature of the relationship between them and their handicapped child. Throughout contact with these parents the development of an unusually close emotional tie between the parents and the handicapped children has been repeatedly demonstrated, one which inhibits independent development of the child and which often gives rise to an exclusive and demanding reorientation of the parent to the child in such a manner that other relationships and interests wither for the parent. A secondary involvement of siblings in this process may also occur. Most parents of handicapped children show this difficulty to some extent and some parents demonstrate it to an extreme degree. It would appear that while the parent and child are present together, the child is unable to liberate himself from an orientation to and dependence upon the parent, and the parent similarly is painfully exclusively oriented and related to the handicapped child, often continuing to foster an immature and dependent relationship with the child; hence the term, "Mutually Inhibiting Parent-Child Symbiosis" is used.

Siblings of the Handicapped

A common occurrence among siblings of the handicapped is the development of attitudes and behavior toward the handicapped child similar to those the parents developed, i.e. interest and solicitude and mothering care directed toward the handicapped child and associated with denial of

his own childlike needs. This may lead to pseudomaturity in the sibling. The danger faced by the pseudomature child is that under stress, the birth of a sibling, a move, illness, pressure from the environment or fear from within, etc., the child may suddenly decompensate psychologically and regress back to infantile modes of behavior and functioning.

Attitudes of Society

It may be assumed that because large sums of money are appropriated by federal and state governments and contributed through privately sponsored campaigns, society is accepting the handicapped person because they have shown their willingness to take care of him. This is not so. A more accurate statement of our current social attitude toward the handicapped person is, "I'll contribute to his care but please don't bring him too close as I do not wish to be reminded of defects and incapacities." Some kinds of defects are more anxiety provoking in this society than others.

Acquired Handicaps, Special Problems

One of the implications of being different from the way one used to be is shown in the case of acquired handicaps. For example, the child with polio, who before his handicap has been successful in many ways physically, faces the task of altering his mental image of his body and therefore altering broader concepts of the self. He may, because of muscular paralysis, be forced to change certain modes of expression. For example, aggressive impulses expressed by physical means now must be expressed by verbal and intellectual methods. The use of passive aggressiveness, passive dependency, and psychic masochism may come into play. Old conflicts in areas surrounding dependency, sexuality and aggression may be stirred up. The struggle in dealing with these problems may lead to psychological growth or psychological decompensation. Even psychosis may result. The resolution of these conflicts favorably will depend upon the emotional maturity of the person prior to the handicap, self concepts established prior to the handicap and the alteration of these to meet the new changes brought by the handicap, and the opportunity to be accepted and loved and to feel secure in the presence of the other persons in the current environment. Such supporting family members must adapt their own expectations and feelings to the new role of handicap in their child. Also of importance is the acceptance by society of the specific kind of handicap. In a family situation in which the handicapped person is accurately perceived by his parents, where his needs are realistically met and where he himself gains an accurate appraisal of his own limitations together with his own capacities, the individual may emerge psychologically healthy. Such success is not met without great individual struggle, for the person has to deal with his own normal problems together with and often confused with problems relating to the handicapping condition. Having emerged from the family situation in a psychologically healthy state, the individual then is confronted with a whole new set of problems, those presented by society, i.e., neighborhood, school, vocational limitations, attitudes of others toward him because of what feelings his defect or abnormality stirs up in them.

Clinical Examples: Children with transcarpal amputation (absence of a part of the hand) show more psychological problems in acceptance of and use of a prosthetic device than do children who have short-below-elbow amputations (most of the forearm missing). Parents of such children have corresponding difficulties. In the case of the child with transcarpal amputation, the parents and the child may both deny the presence of a handicap with greater conviction than in the case of the short-below-elbow amputation. This is because there is a smaller part of the extremity missing. Also such children have the feeling of being "cheated". The child with the short-below-elbow amputation may have the full status of a handicapped person rather than feeling cheated. For example, one girl with the transcarpal amputation who was provided a prosthetic device and refused to wear it. She said that if she wore it people would notice that she was handicapped.

A two-year-old boy with a short-below-elbow amputation had a prosthetic device applied at six months of age. When it was removed for adjustment and inspection in an examination the child dashed into a burning house to retrieve his short-below-elbow prosthetic device and suffered serious burns in recovering it. He said, "I had to get my arm." Instances such as these illustrate the fact that when the prosthetic device is applied early it becomes part of the child's body image, both in his physical and functional aspects. The child's feelings toward the prosthesis are the counterpart of the adult's feelings about the missing extremities which occur as a result of injury, the so-called phantom limb syndrome. The situation of course is reversed. The child adopts the prosthetic device as a part of his own body image whereas the adult with the missing extremity retains the mental image of the extremity which is missing and behaves as if it is still there.

An adolescent girl with a transcarpal amputation is fitted for prosthesis which would enable her to do clerical work more easily. She is fairly mature and does well in school. Yet she refuses the prosthesis with the comment, "No one notices my missing fingers and that device would make them think that something was wrong with me." Further attempts to help her accept the device even in limited circumstances proved unsuccessful. To accept the device for her would have meant admitting that a specific defect was present and would undo her defensive denial about being handicapped. Also this girl's refusal to wear a device illustrates the importance of outer appearances of the body itself, especially to girls at this age. This specific concern about the form of the body itself has its earlier origin in the little girl's feeling of inferiority when she discovered she had no penis and in the older girl's interest in her breast development.

Cerebral Palsy: At a group meeting of parents of young children with cerebral palsy Mrs. S. commented in this way, "You know, Doctor, I've had the strangest feelings about Michael (2½ years old). We didn't know anything was wrong until he was about 17 months old. We took him to the doctor because he wasn't walking. It was then that we were told he had cerebral palsy. Ever since then I've had an unusually close feeling toward him. I've felt that he was actually a part of me. It was a strange feeling and I haven't dared tell anyone about it except my husband. Before we knew he had cerebral palsy I felt about the same toward him as I do to Marilyn (normal sibling, age 4) and we used to leave him with baby-sitters occasionally. Since then

I haven't left him with sitters and I've tried to do a lot more for him. I sometimes think he might be better off if I had been able to continue with him as I had before I knew there was anything wrong." Mrs. S. feels so close to her handicapped child that she is unable to perceive him as an individual and hence recognize either the real nature of the handicap or the child as an individual. It would be realistic to expect that in a child with a handicap which itself delayed motor development, more prolonged dependence upon the mother would occur and hence the child and parent would have greater difficulty in progressing from this relationship to a more mature level of functioning. The presence and operation of factors out of awareness and understanding which unduly promote and prolong this relationship is attested to by Mrs. S's description of Michael as part of herself, for which no realistic reason is evident. Such a feeling, even though unrealistic and unexplainable to Mrs. S. made it difficult for her to perceive Michael as capable of independent development and separation from her. This problem is apparently partially resolved by Mrs. S's ability to bring it into the open and also by the assurances she received as Michael made some developmental progress.

The Bureau of Vocational Rehabilitation in California has found that the degree of physical handicap in cerebral palsied adults is often not of primary importance in predicting success on job training programs and eventual placement in jobs. This finding is not surprising when one considers the factors outlined in this report which influence the degree of functional impairment such as the degree of the individual to realistically perceive himself, the inference of the family social influences, etc. This problem is taken up in some detail in another paper.

Shakespeare's Richard III, The Duke of Gloucester, states:

But I, that am not shapes for sportive tricks,
Nor made to court an amorous looking-glass;
I, that am rudely stamp'd, and want love's majesty
To strut before a wanton ambling nymph;
I, that am curtail'd of this fair proportion,
Cheated of feature by dissembling Nature,
Deform'd, unfinish'd, sent before my time,
Into this breathing world, scarce half made up,
And that so lamely and unfashionable,
That dogs bark at me as I halt by them;

* * * * *

And therefore, since I cannot prove a lover,
To entertain these fair well-spoken days,
I am determined to prove a villain,
And hate the idle pleasures of these days.

As one reads through the remainder of this story and reviews the reign of Richard III, one may pick up a number of insights into the relationship of a handicapped person's relationship to other people, to society,

and his struggles with himself when the psychological problems involved in the handicap are not resolved. Shakespeare's way of expressing the cause of the handicap, "...cursed from my mother's womb," illustrates also the feelings of the handicap being a punishment for sin (in the mind of the mother) and makes understandable and provides an illustration for the motivation of the child's capacity to control and restrict the parents by manipulating parental guilt.

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Problems in the Raising of Deaf-Blind Children

Alice Nemon

Impact on Family

Let us discuss the impact of having and caring for a deaf-blind child on the family. Some factors are shared with families of any handicapped child but some are more specifically an outgrowth of the nature of the handicap itself.

"The birth of a normal child into a family is in itself a potential life crisis. The life style of the family members is almost always drastically changed and a re-adjustment of roles within the family must be achieved. The ability of each family to welcome the arrival of a small, entirely dependent human being depends on the maturity of the parents, their sense of self-esteem as persons and spouses, and their willingness and ability to receive a child of a particular sex and a particular temperament at this specific moment in their lives. The child-to-be is usually seen as an idealized human being who will be able to meet or surpass his parents' achievement and is seen as generally giving pleasure. Nevertheless, from early pregnancy onward the same idealized child may well frustrate some parental needs, evoking resentment on occasion.

"...If the child is not perfect, latent conflicts are revived even in the most adjusted of parents. During the process of suspecting, recognizing, and identifying the handicap, it would appear that the following emotions are common among parents: shock, bewilderment, sorrow, guilt, and anxiety. Anxiety is a frequent spectre and 'tugs' at parental self-esteem and effectiveness prior to the diagnosis, at the time of the diagnosis, and for many months thereafter...

"...Anxiety is an unpleasant emotion characterized by such physiological changes as increased heart rate, breathing, sweating and trembling..." (Schlesinger and Meadow).

We know from our work with families of deaf children that most often it was the parents and grandparents (86% of the time - Fellen Dorf) who first suspected deafness. Too often they were given false reassurances by well-meaning professionals. Some mothers were told they were neurotic worriers. Of course, they wanted to believe the reassurances about the child, but still they had nagging doubts. So we have parents feeling anxious and at the same time doubting their perceptions and

themselves as parents and people. Finally, after searching with a series of professionals, a diagnosis is made. Shock, sorrow, and relief are mixed. At least they have a diagnosis.

As adults we often retain some residue of the magical thinking we did as children. The thoughts and feelings tumble together, "Why did this happen to me?" "I don't deserve this. It isn't fair. I never did anything to anybody." "I had bad thoughts. I did bad things. I am being punished." "Did I do something to cause this? Could I have done something to prevent this? Am I a defective person to have produced an imperfect child? Whose side of the family caused this? I don't want it to be me or my side." Also "It is too much to take. Maybe if I deny that it is happening it will all go away." Then comes the hope for a miraculous cure. Out of a combination of wish, inexperience and natural ignorance there is the hope that hearing aids will make the child hear normally, that there must be something definite the doctors can do.

Gradually the impact is felt -- the dreams of normalcy die. These are dreams we all have for our children. When we are faced with a loss, a death, we mourn. We need to mourn. If we don't it is not possible for us to work through our loss. Now I am talking about the loss of the dream, not the child. Ross in The Exceptional Child in the Family talks of how sorrow, often chronic, if allowed by mourning for the loss of the expected perfect child.

Grief and Anger

Parents need to admit to themselves and each other their grief and anger. I am not suggesting that this will make them accept the situation in the sense that acceptance means it is allright. It is not and never will be allright. But if one can at least acknowledge the feelings of "I don't want this. I feel miserable," one is not expending emotional energy in denying feelings and may be able to use that energy for helping himself, the family and the child.

Because parents feel it is unacceptable to have negative feelings about a child these feelings are translated into feelings of guilt (Schlesinger and Meadow). Again guilt drains the energy that could be otherwise used. Also guilt prevents one from seeing things as they really are. At the Mental Health Services for the Deaf we see some children perceived by their parents to be "sainted angels," or "disabled waifs," rather than as the children they really are.

Support

Parents cope with the birth of a handicapped child in different ways. They may have learned from past life crises how to find out what can be helpful to them from within and without. They may turn to relatives and friends for support. They turn to experts, doctors, teachers, social workers, and books for information and support. Parents may develop strengths they didn't know they had. Often they find much help from meeting with other parents of similar children to share their feelings, experiences, information, and ideas.

The parents learn that they will have to search out the best available help for their child. Some people are more assertive than others. With normal children such assertiveness may not be necessary during their entire development. The parents of children with a handicap, however, may note that resources may be inadequate or nonexistent and may need to "push." Such a surge of assertiveness may feel uncomfortable, may be inconsistent with the parents' self image, but may be very necessary to create new avenues of help for themselves and their children.

Dependency

Initially, during infancy and early childhood the child with a handicap will require more time, more care, more effort than a healthy child. Frequently, however, this develops into a mutual dependency relationship that is counter-productive for either child or parent or both. If such an outcome can be anticipated and prevented, child and parent will benefit.

Of course, the real demands on parents are very heavy. It is important that they see for themselves, the rest of the family, and the child, the value of maintaining other interests in life. We see situations where the mother can get so wrapped up in the handicapped child that she excludes her husband and her other children because they seem to need her less. The husband may feel his wife is there only for the child, not for him, and may feel like an outsider. Perhaps here the mother may cut off a potential source of support and help with the child. If the mother didn't need to feel she was the sole source of care for the child, she might let her husband help her more with the arduous task of caring for the child. Also, sometimes the father, who is away from home more, can come to the situation with a little more perspective and distance. It may not be easy to hear him say some of what he observes, i.e., "You are too overprotective. You are doing too much for him. The other children's needs are taking a back seat," or "I need to get away from it all for a weekend alone with you." In mental health it is a cardinal principle that when a person has received, it is easier for him to give. This applies not only to children but to mothers and fathers as well. If possible they need to be replenished themselves in order to be more giving to their children, handicapped or normal. People are given to in different ways -- through spouses, friends, special interests, hobbies, and work. Sometimes, when a parent's own self esteem feels much in doubt it seems easier not to venture out in these areas but to remain closely tied to the handicapped child where one knows one is needed.

Facilitation vs. Extension

Parents of deaf-blind children learn that they are most important as facilitators of their children's development and motivation. They will need to guide their child's hands many times in various tasks before he does the tasks himself. They will need to sit behind him, moving parts of him to help him experience certain sensations of how to do things for himself. These very necessary tasks make it more likely that they may see the child and themselves as extensions of each other. I feel this is a

very important potential problem to be aware of. For if the child and parent remain extensions of each other both physically and psychologically, the child will not be able to develop his sense of "I" and whatever degree of independence he can attain. I do not advocate withholding parental involvement, but I feel it is important to distinguish between being a facilitator for the child and an extension of him.

The Sense of "I"

Despite the existence of sensory impairment, the main task of developing an independent human being is to provide a sense of "I." The child begins with "I am what I am given," and goes on to, "I am what I can do." Later still he recognizes, "I am what I can learn," (Erickson). Because of the obviously heavy needs of the deaf-blind child it is easy to get into the bind of placing overly heavy emphasis on giving. But it is good for parents to keep in mind that their goal is, "I am what I can do. I am what I can learn." So as much as possible in each area, parents need to enable the child to get to the point of experiencing, "I can do it!"

It is important that parents, when the first glimmers of achievement show after all their hard work, give the child the message, "Go ahead, this I know you can do." The glimmers are often small; a beginning tug on his own pants to pull them up; a readiness to hold his own spoon after the parents have held their own hands over his on the spoon a hundred times to help him experience it tactually and motorically. In the New York study of Rubella children, the children were given three times as much help as needed (36.6%) because of time pressures and to allay parents' discomfort at seeing the child struggle, often preventing him from optimizing his self reliance.

Parents are Only Human

Parents will not be able to give all the time. Sometimes they will be discouraged, or tired, or busy. If they feel too guilty about doing less for the child, it can be harder on them. Even when this is not the case, they may still feel guilty, thinking, "If I were a more perfect, dedicated parent my child would be more independent." Now, of course, greater independence is the goal, but parents aren't saints. If they are realistic about not expecting saintliness of themselves they may come around to realizing that they have actually done a great deal. One hundred percent self-discipline about everything - or anything - is rarely to be found, or to be believed. Maybe if parents were less concerned about their lapses they could be freer to try again the next day when they were fresher and less pressed. I am not advocating neglecting techniques for involving the children in concept and language development, experiential learning, general attentiveness-development, and fostering the use of residual hearing and vision. These are all essential to pull the child away from a tendency to isolation. I am suggesting that when parents realize they have not been the complete mother, teacher, specialist, they also realize that no one else is either. This does not make them bad parents. They are human beings weighted down with a heavy burden, struggling courageously against great odds. Sometimes they may stumble, fall, lose a little ground -- then they

pick up and move on again.

Siblings and Discipline

There are two more related areas I want to touch on that we have found to be of concern to parents of children with a handicap. They are siblings and discipline. We have seen that often the siblings of the handicapped child may behave in ways that are prematurely older or more responsible than their age warrants. It is important as much as possible to let them have a childhood too. They may feel anger at their handicapped sibling and all the attention he gets. But think of how guilty the normal child can feel about being angry at someone so unfortunate. He may also feel, "There but for the Grace of God, go I." Parents can help their normal children to express their hostility and guilt by admitting that they sometimes feel the same way. Thoughts and feelings don't kill, so one need not expend endless energy in denying them. Normal children may feel protective and at the same time ashamed of their handicapped siblings in front of others. They may not say this, but may manage to play at friends' homes all the time and never invite the friends home in return. It may be important for parents to let their normal children know they will arrange for the handicapped sibling to be otherwise occupied and not always the center of attention or even present. That is not like the old fashioned "hiding away." We now have come to recognize that even normal little brothers need not always be tagging along, because each child needs some separateness. This holds true for the handicapped child as well.

The normal child may feel that in addition to the extra attention his parents give the handicapped child they favor him by letting him get away with more. This brings us to the problem of discipline. It is very understandable that many of the parents we see whose children do not have language feel at an impasse about discipline. They are torn. Often the behavior of the child reflects the fact that he does not understand what the parent wants or doesn't want. In some children, when they have developed language through total communication, there is often a marked diminution of behavior problems. Unfortunately, after years of little or no communication and the attendant frustration of child and parents, not all behavior problems respond readily. Parents and children can get into mutually unhappy situations. Children who understand little else may readily understand that Mother will give in to more candy in the supermarket so as not to have Junior create a scene, and scenes attract unpleasant attention. It is hard enough to endure the stares or deliberately averted gazes for the child's differentness without adding a tantrum.

Parents may need to anticipate, perhaps giving the child something specific to munch on almost ritually, or a chance to select one item while they shop. This can be both a helpful exercise for the child in making choices and for both parent and child in limit-setting. The specifics cannot all be dealt with here. Limits and discipline need to be as much a part of the life of the handicapped child as for the normal child. It is frightening to a child if he is too powerful. If he can control everyone around him he is not going to feel he can get help from others in controlling his own impulses.

We have seen one tiny five-year-old deaf-blind child described as "Atilla the Hun" because of the power she was given by the family. It might be difficult to feel loving toward Atilla the Hun. Parents feel impotent when ruled by their children; siblings feel resentful, and the child himself feels the reversal of roles. Therefore, discipline is important for the child and the entire family.

Summary

Parents of a child with a handicap share the same dreams as parents of any children. Obstacles invariably get in the way of achieving these dreams. The removal of many obstacles await medical and technological advances. Many, however, can be eliminated as of now, some by sharing the care and the burden of the child, some by clarification of the actual versus the imagined special needs of the child, and still others by providing the most optimal and unconflicted sensory input possible for the child. Foremost, however, seems to be the realization that parents and siblings have a life of their own which must be lived as productively and satisfactorily as possible for their own sakes as well as for that of their deaf-blind child.